

SOCIAL BARRIERS TO PHYSICAL ACTIVITY FOR INDIVIDUALS WITH PHYSICAL
DISABILITIES

RESEARCH THESIS

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ABSTRACT

The purpose of this thesis was to explore socially constructed discursive barriers to physical activity for people with physical disabilities through the lens of physical activity guidelines and other promotional materials aimed at increasing physical activity among the Canadian population. This research was informed by a critical disability studies framework. Interviews with four people with physical disabilities (end-users), as well as four individuals involved in the development of physical activity guidelines and resources for people with physical disabilities (stakeholders) were digitally recorded, transcribed, and then analyzed using critical discourse analysis. The results were then divided into two articles, the first discussing the perspectives of the end-users with regard to their own physical activity participation, their use of currently available PA resources, and their views of disability and how it is constructed. The second article dealt with the views of the stakeholders with regard to Canada's progress in creating inclusive PA guidelines, the research process as it affects people with physical disabilities, and how disability is constructed. In the first article, the end-users constructed disability in largely medical terms, displayed their disappointment with current PA guidelines, and offered suggestions for improvement, such as creating guidelines with a more holistic approach to health. The critical discourse analysis revealed that negative perceptions of disability among the general population contribute to the problem of physical inactivity, and that greater knowledge among those with disabilities, such as from appropriate PA guidelines, could help alleviate this problem. In the second article, the stakeholders revealed that lack of funding from various levels of government has held back their research programs and advocacy efforts, resulting in insufficient PA resources for people with physical disabilities. A focus on the medical definition

of disability was also a prominent theme. Across both groups, the need for an organized movement of people to advocate for disability issues, including PA promotion, was expressed.

Table of Contents

Acknowledgements	ii
Abstract	iii
Chapter I: Introduction	1
Introduction	1
Literature Review	4
Physical Activity Guidelines and Physical Disability	5
Impact of Physical Inactivity on Those with Physical Disabilities	9
Strategies for Greater Inclusion in Physical Activity Within this Population	10
Theoretical Framework	18
Framing Disability	23
Models of Disability in Contrast with Social Deviance	25
Critical Disability Studies as a Tool for Social Change	27
Citizenship and Personhood	29
Language Issues	31
Active Bodies with Disabilities	33
Methodological Framework	34
Methods	39
Thesis Outline	42
Chapter II: Effectiveness of Current Physical Activity Guidelines Among Sample of Canadians with Physical Disabilities	43

Abstract	44
Key Words	44
Introduction	45
Method	48
Participants	48
Data Analysis	50
Findings – Theoretical Themes	53
Findings – Practical Themes	60
Discussion	67
Limitations	70
Conclusion	70
References	73

Chapter III: A Discourse Analysis of Canadian Health Promotion Resources: The

Stakeholders’ Perspective	76
Abstract	77
Key Words	78
Introduction	79
Method	82
Participants	83
Data Collection	84
Data Analysis	85
Findings	86

Health Promotion Materials in Canada	87
Current Initiatives Geared Towards People with Disabilities	89
Strategies to Address Physical Inactivity Among Those with Disabilities	91
Strategies to Improve the Delivery of Health Promotion Services	94
Problematic Discourses Contributing to the Problem	96
Limitations	101
Conclusion	101
Future Research	102
References	103
Chapter IV: Summary of Findings and Conclusion	106
References	118
Appendices	127

List of Tables and Appendices

Data Analysis Method	51
End-User Categories/Themes	52
Definitions of Disability	54
Stakeholder Categories/Themes	86
Current Canadian Physical Activity Resources	89
Appendix A: Interview Guides	127
Appendix B: Script for PARA-SCI	130
Appendix C: Physical Activity Guidelines Materials Reviewed	131

Chapter 1

Introduction

Physical inactivity has been identified as a national concern in Canada that carries with it an economic burden on the health-care system, as well as the personal toll of ill health for thousands of Canadians (Warburton, Whitney Nicol & Bredin, 2006). While Martin Ginis and Hicks (2007) reported that 35% of Canadians are physically inactive, the situation for those with physical disabilities is even more serious, with 56% of people with physical disabilities classified as inactive. According to 2006 Statistics Canada data, the incidence of disability in Canada is fifteen percent. While Canada has made progress in the areas of full inclusion and accessibility for those with physical disabilities, especially in terms of accessibility policy on the provincial level, there remains distinct and significant areas for improvement. One of these areas is physical activity. People with physical disabilities, including those with spinal cord injury, are one of the least active segments of the population (Martin Ginis & Hicks, 2005). Despite the wealth of evidence regarding the benefits of physical activity (Pate, et al., 1995, Warburton, et al.), there have been no evidence-based guidelines for physical activity for people with physical disabilities until very recently (SCI Action Canada, 2011). The potential implications of physical inactivity for those with physical disabilities includes increased risk for chronic diseases, such as heart disease, obesity and type two diabetes (Martin Ginis, Latimer, Hicks & Craven, 2005). Hence, a solution to this problem is both a pressing social, and long-term population health concern.

There are competing notions of how to define disability. Traditionally, disability has been viewed in medical terms as a disease or pathology that exists within a person, causing some impairment or limitation (Donoghue, 2003). All types of disabilities were originally defined in

this way, with no reference to the social factors that contribute to the experience of disability (Donoghue). Since the 1970's, more scholarly attention has been paid to the social experience of disability, resulting in what is known as the social model of disability (Shakespeare, 2008). In this model, disability is a social issue wherein people with disabilities are not given the tools and resources they require to fully participate in all areas of society (Thomas, 2007). The World Health Organization (WHO) has also recently provided a framework for defining and studying disability that accounts for both medical and social issues that affect people with disabilities (WHO, 2012). While this framework has been used in a number of contexts, critical disability scholars have endorsed the social model and situated their research within it (Shakespeare). Health promotion research has traditionally been conducted within the medical framework of disability, emphasizing functional limitations and impairment, while largely ignoring the role of social barriers to physical activity (Martin Ginis & Hicks, 2007). In this study, I will use the social model of disability as a framework to explore the lived experiences of people with disabilities with respect to accessing physical activity resources, as well as to analyze the biases within the health promotion research program in Canada as it pertains providing resources and guidelines to people with physical disabilities affecting mobility.

My research questions are what are some of the barriers experienced by Canadians with physical disabilities with regard to the provision of physical activity and health resources? Barriers can include issues of physical access, attitudinal barriers and psychological barriers on the part of people with disabilities. As well, barriers can also be issues of funding, insufficient or ineffective advocacy, and unclear expectations of who bears the responsibility for the inclusion of people with disabilities in this sphere of activity. Further, what gaps in the research, as well as the delivery of services and advocacy for people with physical disabilities have yet to be

addressed by policy initiatives and equitable funding priorities? Lastly, how do the discursive concepts of the medical and social models of disability interact to impact the opportunities for physical activity participation among this population? This line of questioning enabled me to identify the systemic and social barriers that prevent full inclusion in government literature on physical activity in Canada, including physical activity guidelines, for people with physical disabilities, as well as explain why physical activity levels in this population are low in order to address some of the underlying issues. In order to understand the complexity of these barriers, it is important to look at the history and development of physical activity guidelines in Canada, the discourses surrounding physical disability, the biomedical and social models of disability, as well as constructions of the active disabled body. As such, also under investigation is whether dominant ableist discourses present in physical activity guidelines are contributing factors in preventing people with physical disabilities from participating in physical activity.

Research in the area of discourse and disability has demonstrated that discourse plays an important role in limiting the opportunities available to people with disabilities in various spheres of life, such as sexual function (Tepper, 2000), employment (Lunt & Thornton, 1994), and the overall perception of bodily dysfunction in society (Hughes & Paterson, 1997). In this project I explored the role of discourse in facilitating or hindering physical activity participation among people with disabilities of mobility.

This research project is situated within the theoretical framework of critical disability studies. Critical discourse analysis is my research methodology, as I believe that research of this nature can and should include a component of emancipation and advocacy for those segments of the population that are so often silenced and excluded from the dominant discourses (Grue, 2011). As an individual with a physical disability (spinal cord injury), I recognize the need for

reflexivity throughout all steps of the research process. In the tradition of qualitative research, I am simply stating my position in relation to the subject of physical activity for people with physical disabilities. My background also includes training in exercise physiology and personal training. In this study, I situated my research within the social model of disability that focuses on societal constraints.

Literature Review

The social construction of dis/ability, as well as other variables, plays an important role in patterns of physical activity and inactivity throughout the lifespan (Rimmer, 1999). In this literature review I will highlight the connections between bodily constructions of disability and the overall literature on physical activity guidelines, as well as larger issues of inclusion and exclusion of groups in society based on disability. These variables all have their own complex sociological constructions with which they are associated; however, I plan on addressing the literature only pertaining to issues that relate in some way to disability and physical activity. I will organize this literature review into three sections: the first is a review of current physical activity guidelines and materials in Canada and elsewhere in the developed world; the second is the impact of the exclusion of those with physical disabilities from those materials; and the third section will address strategies identified in the literature to address this exclusion.

The references for this literature review were found using the University of Ottawa library database. The search terms used were physical activity, disability, social model, medical model, physical activity guidelines, stigma, and discourse analysis.

Physical Activity Guidelines and Physical Disability

There is a substantial body of literature on the topic of physical activity guidelines in Canada. Recent studies explore the development of physical activity guidelines (Tremblay, Shephard & Brawley, 2007), the history of physical activity policy in Canada (Sharrat & Hearst, 2007), future directions in public policy with respect to physical activity (Tremblay, et al., 2007), as well as a significant body of literature on measuring levels and impacts of physical activity on health and well-being (Fortier, Sweet, O'Sullivan & Williams, 2007; Kowal & Fortier, 2007). There is a growing recognition of the importance of examining multiple variables that impact physical activity levels. Recent studies investigated how factors such as age and chronic illness need to be addressed in order to meet the needs of different segments of the population (Chun & O'Connor, 2011; Dumas, Laberge & Straka, 2005; Sigal, Kenny, Wasserman & Castaneda-Sceppa, 2004.) In my opinion, there remains an important gap in the literature as needs of individuals with physical disabilities are not addressed in traditional physical activity guidelines (Martin Ginis & Hicks, 2007). The data produced from measuring physical activity levels does not mention physical disability as a consideration, nor are statistics provided on physical activity among those with physical disabilities (Statistics Canada, 2010).

While there has been considerable research conducted on the Canadian physical activity guidelines, the research topics have rarely considered the exclusion of Canadians with physical disabilities from those guidelines. Only one Canadian peer-reviewed article has made a formal recommendation for the development of such guidelines (Martin Ginis & Hicks, 2007). Since that article was published, this same research team received funding (from a private organization) to establish a set of guidelines for people with spinal cord injuries (SCI Action Canada, 2011). The development of these guidelines is a significant step forward in this area,

and my research contributes to this growing body of knowledge. My thesis will explore issues of inclusion and exclusion in public policy and academic research initiatives by interviewing two groups of people – stakeholders involved in research and programming, as well as individuals living with physical disabilities.

Canada is only one example of a developed country that has created policy to promote an active lifestyle among its population. Other countries, such as the United States and the United Kingdom have also developed physical activity guidelines that are used to combat the growing issue of physical inactivity, and its associated morbidities. Studying the guidelines developed by these countries provides an opportunity to assess whether Canada is (1) keeping pace with other nations in terms of access to physical activity and health resources for those with physical disabilities, and (2) to assess where Canada can co-opt inclusive that were effective in other countries.

Health Canada and the Canadian Society for Exercise Physiology (CSEP) published the original Canadian physical activity guidelines in 1998 (Sharratt & Hearst, 2007). Since then, the guidelines were updated in 1999 and in 2002 for children and youth. Subsequently, a guide was also developed for older adults. In 2004, the CSEP evaluated the current guidelines, and in 2010, the guidelines were revised once again to reflect the most recent developments in research on physical activity and types and dosages required to affect health benefits (Tremblay, et al., 2011). The new guidelines are the result of five separate systematic reviews of the relevant literature and a rigorous review process of determining which results would be in/excluded in the recommendations. There were thousands of articles and studies to choose from, making the inclusion process difficult for those involved (Tremblay, et al.). In contrast, the recent efforts by Hicks, et al. (2011) to formulate a systematic review of the literature on the benefits of physical

activity for those with spinal cord injuries included only 82 studies deemed sufficiently relevant and scientifically rigorous to be included. In examining the barriers to physical activity among people with physical disabilities, it is important to note barriers not only in the physical and social environments, but also those that stem from research biases and the lack of available quality research to guide physical activity recommendations among this population. Not only is the social construction of disability an important consideration in my proposed study, but the social construction of research itself, and the bias involved in determining strategic research priorities of government funding.

The *American Physical Activity Guidelines* (U.S. Department of Health and Human Services, 2008) include considerations for adults with different disabilities and chronic diseases, and also delineates specific guidelines for adults with disabilities. The types of conditions these guidelines include ranges from spinal cord injury and cerebral palsy to intellectual disabilities and dementia. In their description of the literature surrounding the concept of disability, Devlin and Pothier (2005) did not differentiate between physical and intellectual disabilities due to the similar societal barriers faced by people who deal with these limitations. For the purpose of research on physical activity, however, equating these two types of disabilities makes little practical sense, as the physical limitations faced by either population are vastly different, though many of the social barriers remain the same.

In Canada (CSEP, 2011) and the United Kingdom (National Health Service, 2010), the physical activity guidelines developed by the cited government agencies do not include specific physical activity recommendations for people with physical or intellectual disabilities, nor do the general guidelines include considerations for disabilities. According to Sharratt and Hearst (2007), the Canadian physical activity guidelines developed in the 1990's were intended to be

adaptable for different segments of the population, including those with disabilities, as the guidelines were general enough. However, the lack of reference to disability and the dominant discourse of ableism that is perpetuated by the guidelines render these guidelines as an insufficient resource for people with disabilities. Importantly, the guidelines fail to provide strategies for how to incorporate physical activity into daily life for those who use wheelchairs and other mobility aids such as canes and walkers, and make no reference to intellectual disabilities. Additionally, many of the recommendations made in the guidelines are inappropriate or even dangerous for individuals with certain limitations (Martin Ginis & Hicks, 2007). Sharratt and Hearst conceded that the guidelines are not the best resource for those with disabilities, and recommended that people with disabilities consult with their appropriate health professionals before undertaking a physical activity regime.

The impact of this exclusion is currently studied in terms of physical inactivity among those with physical disabilities, but larger issues of citizenship and personhood are not yet well explored with respect to exclusion from physical activity resources. In the next section of this literature review, I will review key literature on physical activity patterns and impacts among those with physical disabilities, as well as the literature that addresses barriers to accessing physical activity resources and facilities.

Impact of Physical Inactivity on those with Physical Disabilities

Over the last 30 years, a vast number of studies have been conducted in the area of physical activity with respect to the physiological (Warburton, Nicol & Bredin, 2006), psychological (Hassmen, Koivula & Uutela, 2000) and economic benefits (Katzmarzyk, Gledhill & Shephard, 2000) of regular physical activity among the general population. There has been,

and continues to be, a lack of quality physical activity research conducted on and with individuals with disabilities, and the knowledge base concerning the benefits of physical activity for these populations is incomplete (Hicks, et al., 2011).

Most of the research on physical activity for those with disabilities is focused on the physical barriers they face in accessing physical activity. Some of the major barriers include environmental issues of physical inaccessibility to fitness facilities, economic issues, psychological barriers and attitudinal barriers among those employed at fitness facilities (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Rimmer, Rubin and Braddock (2000) reported that a plurality (37% of their sample) of women with physical disabilities report that they would like to begin incorporating physical activity into their lifestyle, but cite lack of knowledge as a significant barrier. It is also important to review, however, the impact of this exclusion in terms of rates of participation among those with physical disabilities, as well as overall health status.

Martin Ginis and Hicks (2007) recorded important epidemiological data on the health status of those with physical disabilities, providing important context of the issue I plan to address in my study. They reported that only 31% of those with disabilities describe their health as very good or excellent, versus 71% of Canadians without disabilities who categorize their health that way. Furthermore, Canadians with disabilities have more hospital stays, take more prescription medications and are at higher risk for metabolic illnesses, such as diabetes and heart disease. In terms of physical inactivity, Martin Ginis and Hicks reported that 56% of Canadians with disabilities are inactive, compared to 35% of Canadians without disabilities. Although they did not imply a causal relationship, Martin Ginis and Hicks pointed out the dearth of policy initiatives aimed at increasing physical activity and overall health status among this population.

These findings point to a troubling impact of the lack of physical activity resources for those with physical disabilities, and emphasize the need for research and action in this area.

Rimmer, et al.'s (2000) and others' findings suggest that lack of information is a significant barrier to physical activity among those with disabilities. The lack of information refers not only to the promotional efforts that are targeted towards the general population while not addressing the needs of those with disabilities, but also to the lack of information among fitness professionals with respect to how to incorporate different strategies to meet a wide range of needs (Rimmer, 2002). Rimmer, et al. (1999) reported that half of his sample of women with physical disabilities felt that the fitness and recreation facilities available to them would be able to meet their needs. These findings point to a troubling lack of knowledge flow (1) from health and fitness professionals to clients and patients with disabilities, and (2) from the research community to health and fitness professionals. In the following section, I will review the literature that identifies strategies and recommendations on ensuring a more inclusive approach to understanding and promoting physical activity for those with physical disabilities.

Strategies for Greater Inclusion in Physical Activity Within this Population

Within the literature on physical activity exclusion among individuals with physical disabilities, a number of possible strategies are revealed: (1) reconceptualize the concept of disability within the research community; (2) identify and demystify dominant discourses of ableness that shape current norms, perceptions and policies; and (3) synthesize policy at various levels of the Canadian government to promote inclusion and fill the gaps in current policy initiatives.

The social model of disability is rooted in the idea of societal constraints as a main barrier to full participation in society, rather than functional limitations (Samaha, 2007). The characterization of disability as a social construct is contested in the literature on disability, but has gained momentum in the past 30 years (Samaha). The importance of this concept is that it differentiates the concept of impairment, a product of the biomedical characterization of disability, from the lived experiences of those with disabilities who encounter different levels of constraint (Samaha). The social model of disability focuses on the societal factors that contribute to how individuals and groups perceive disability, and places the responsibility for constraints and exclusion on a society that is inherently constraining, as opposed to biological limitations that impact full participation in society (Britain, 2004).

Siebers (2001) and Erevelles (2000) noted that the social construction of disabled bodies in society proves a useful framework for analyzing the social construction of bodies in general. In other words, it is important for researchers to grasp the concept that bodies are not just sets of biological functions; all bodies have social meaning ascribed to them, both as a function of biological parameters and our own interpretations. Synnott (1992) took this idea even further in his analysis of the classical philosophers' conception of the body. Synnott pointed out that philosophers, such as Plato and Socrates, struggled with the very same questions about the body that we still ask today, such as whether it is primarily empowering or constraining, and how to approach bodies that are different, whether as a function of race, age or dis/ability.

In her first-person account of living with a physical disability, Liz Crow (1996) both embraced and criticized the social model of disability and impairment. Crow stated that in conceptualizing physical disability as a social construct, she was able to externalize many issues in her life related to her disability and stop placing all the blame of her body, realizing, instead,

that society itself is disabling. On the other hand, Crow argued that the social model of disability inhibits those who live with disabilities from accepting and dealing with their limitations. Peters, Gabel and Symeonidou (2009) and Winter (2003) brought up a similar issue, that the social model of disability is successfully utilized to demystify the concept of disability and place the onus of responsibility on an oppressive society. However, the embrace of the social model in sociological research has not necessarily translated into more inclusive practice in society. All the authors pointed out the importance of a well-organized political action movement in order to make progress in terms of inclusion. Winter argued that to achieve full participation in society for people with disabilities, researchers and policy makers must let go of restrictive models that look at disability only through one lens (e.g. only as biomedical or only as social constructed), and embrace the multi-faceted concept that constitutes disability.

One of the main strategies for promoting inclusion that I identified through the literature, and lack thereof, is the reconceptualization of disability from the biomedical model to the social model in the wider research community. Martin Ginis and Hicks (2007) remarked that one of the causes of widespread exclusion of people with disabilities from physical activity and health policy is the strict adherence in the research community to the biomedical model of disability, which ignores the role society plays in reinforcing disablement. Martin Ginis and Hicks posited that this model of disability results in the exclusion of those with disabilities from resources, because they are seen as “beyond the reach of health promotion initiatives” (Martin Ginis & Hicks, p. S136). In my literature search, I did not encounter any similar statements with respect to the limits of the biomedical model of disability with respect to health promotion, or any studies that approached this issue from a sociological point of view. One of the potential outcomes this strategy can achieve is a greater sensitivity among researchers and policy makers

towards the effects society has on those with disabilities, and, ultimately result in more incentive to create inclusive policies.

Another strategy to promote inclusion for people with disabilities is to invest effort into identifying and demystifying dominant discourses of ableness that permeate current physical activity and health promotion literature. According to Norman Fairclough, discourses are a “way of signifying experience from a particular perspective” (Titscher, Meyer, Wodak & Vetter, 2000, p. 148). In analyzing discourse, one takes knowledge that is otherwise taken for granted and analyzes it from the appropriate perspective. Analyzing discourse is not a value-neutral undertaking. Researchers who choose to use discourse analysis when conducting their research often make use of explicit theoretical frameworks that guide their approach. An example of this approach is Kang’s (2009) study of a teacher’s perspective of special education. Kang’s explicit goal in this study was to uncover the dominant discourses that teachers confront when dealing with students with disabilities. She did so with the intention of furthering inclusion in the classroom for those with disabilities. A number of studies in the areas of education (Grenier, 2007; Reid & Knight, 2006) and public health (Lollar & Crews, 2003) have used this approach of discourse analysis in order to identify dominant discourses, and to point out where they marginalize and exclude certain groups. This approach, however, has been absent thus far in the literature on physical activity policy and disability (Grue, 2011), an important gap in the literature that I will address in my research, using the social model of disability as a framework for understanding issues of inclusion and exclusion in Canadian society. This is a novel approach in the literature with respect to research on physical activity and exclusion.

The social model of disability has been a positive force in bringing issues of societal barriers into public consciousness (Crow, 1996); however, there are still significant inclusion

gaps in many aspects of life for individuals with physical disabilities, including physical activity participation (Rimmer, et al., 2004). Despite attempts by non-governmental organizations to emphasize the right of all individuals to participate in physical activity, in practice, people with disabilities have been consistently excluded (Mahon, 2003). Inahara (2009) pointed out that the prevailing discourse in the realm of physical activity is one of ableness. The able body is the default position with respect to physical activity and other kinds of bodily displays. In physical activity guidelines in particular, references to walking, running, cycling and other ambulatory activities are prevalent, while references to using wheelchairs, canes, walkers and other mobility aids are all but absent.

The literature on disability and physical activity takes into account the success of the Paralympic Games in seeking to display and celebrate disabled bodies and athletic excellence (Britain, 2009; Hargreaves & Hardin, 2009) among other events, but also points out the need for ongoing improvements in breaking the dominant discourse of ableness. Of particular importance is the discrepancy that exists even within the disabled sporting community between males and females, where male achievement is more visible and celebrated than that of females, an effect compounded for females of colour (Hargreaves & Hardin).

James Rimmer conducted extensive research on people with physical disabilities and their lack of physical activity participation. His conclusions demonstrate that people with physical disabilities are much less likely to engage in physical activity than their able-bodied counterparts, and more males participate than females (Rimmer, 2005). Some of the barriers identified include lack of information, professional knowledge and perceptions and attitudes of those around them, including professionals (Rimmer, et al., 2004). Hardin (2003) pointed out that for an individual with a physical disability, the lack of an “ideal sporting body” (p. 108) is

one of the main barriers to participation. Hardin also posited that sports played by people with disabilities are not seen as real sports, but as something less. It is possible that this discourse contributes to the lack of participation in physical activity, without taking into account high performance sports, such as at the Paralympic Games. There are few athletes with physical disabilities who are famous (Hardin), and this may account for lack of motivation among younger age groups to participate in physical activity and sports. The discourse of making it big and succeeding as a professional athlete is not seen as a possibility for those with physical disabilities the way it is for those who are able-bodied, no matter how remote the possibility, even for physically able individuals (Berger, 2008).

One of the formative processes in developing a lifestyle that includes physical activity is physical education class. Grenier (2007) studied the inclusion of students with physical disabilities into physical education classes. She pointed out the uncomfortable meeting between the biomedical and social models of disability when teachers are confronted with this issue of inclusion in their classrooms. Grenier found that when labels and othering language with respect to students with physical disabilities were dispensed with, attitudes favoured inclusion to a much greater extent than when the students were seen only as a diagnosis, or set of functional limitations. The personal account of living with a physical disability recounted by Eisenman (2003) supported this idea by describing the negative encounters he had with medical professionals who dealt with him as a set of symptoms instead of as a whole person. These examples point to the importance of analyzing the dominant discourses in this area in order to bring issues of inclusion and exclusion to the fore, and to challenge prevailing notions of what is normal, athletic and desirable. An important component of encouraging healthy lifestyle behaviours among those with physical disabilities is health promotion and messaging. The

Canadian Physical Activity Guidelines (CSEP, 2011) is one element of Canada's ongoing attempt to encourage an active lifestyle among Canadians. As such, it is crucial that this guide is inclusive in its provision of guidelines for physical activity and healthy active living, as well as the images, words and discourses that shape its promotion. Additional research directed at analyzing discourse is only the beginning of any comprehensive solution to the issue of exclusion in Canadian society for those with disabilities.

This literature suggests that concrete action in the form of policy is the logical and imperative next step. Policies include not just physical activity guidelines, but extend to the tools the Canadian government uses to measure physical activity and health behaviours of its citizens, and an overall change in perspective on disability. In order to accomplish this, I believe that a shift in model to the social model of disability is needed, as suggested by Martin Ginis and Hicks (2007), as well as an attempt to deconstruct dominant discourses of ableness that permeate Canadian policy.

An important step forward has been made by a group of researchers at McMaster University, where physical activity guidelines have been developed for people with spinal cord injuries (Hicks, et al., 2011). The guidelines were only released in March 2011 (SCI Action Canada, 2011), so it is difficult to assess effectiveness at this point; however, their development is a crucial first step in developing inclusive physical activity and health resources for those with physical disabilities. There remain, however, many types of disabilities for which there are no such resources, and continued support from advocacy organizations, as well as government agencies will be crucial to garner momentum for this project.

In summary, this project will investigate the issue of exclusion from physical activity and health resources for those with physical disabilities, as well as the impacts of this exclusion. This

comprehensive literature review reveals current research pertaining to this issue in the areas of health promotion, disability studies, and critical discourse analysis with respect to marginalized groups in society, but there are conspicuous gaps in the literature in terms of the application of disability studies and the social model of disability to the issue of physical inactivity among those with physical disabilities. Hence, my study will strive to contribute to the literature by framing the issue of physical inactivity among those with disabilities in the context of the social and societal constraints imposed upon that population, rather than the physical and psychological barriers that have been studied thus far. The following chapter outlines the methodological and theoretical framework in which this research is situated.

Theoretical and Methodological Framework

Critical disability theory (CDT) is a relatively new theoretical framework, embraced by academic since the 1970's (Shakespeare, 2008). CDT is built from the foundation of critical theory, but focuses on the rights of people who have disabilities, and the barriers they face in accessing basic rights and services. Critical theory is a school of thought rooted in Marxism that seeks not only to explain society, but also to make the study of society a self-reflexive and critical practice, often with specific political goals in mind (Scott & Marshall, 2009). CDT is an area of study, but it is also a political project. Like other theoretical foundations built on the framework of critical theory, CDT was developed out of reflection that individuals with disabilities had specific issues and concerns that were not being addressed.

The political project of CDT developed throughout the 1960's and 1970's, but in order to understand how it came about, it is important to study the developments in medical sociology dating back to the 1940's and the post World War II time period (Thomas, 2007). The 1950's were the first time in history when a significant portion of the population in the developed world started living with chronic illnesses and disabilities. The increase in prevalence of disability was caused by injured soldiers returning from WWII, combined with advances in medical technology that allowed better diagnostics and treatment (Thomas). The types of injuries that used to be fatal only caused severe injuries, thus, a greater proportion of the population than ever before started living with disabilities. The government and medical professions strived to develop more effective ways to rehabilitate injured war veterans to return to the workforce and assume their previous lifestyle (Thomas). The fields of medicine and medical sociology were at the forefront in treating disabilities and accompanying issues during this post war period, while issues of

accessibility and inclusion were still far from public consciousness (Thomas). While the concept of a 'social model' of disability had not yet been framed in the 1950's, a growing sense of discontent over disability rights and inclusion was developing throughout Canada, the United States and the United Kingdom.

Talcott Parsons was one of the first theorists of medical sociology who wrote about disability in the 1940's and 1950's (Shakespeare, 2008). In dealing with issues of disease and disability, Parsons formulated the concept of the sick role, in which the responsibilities of the person who has an illness or disability include getting better as quickly as possible, and while remaining in that state, to assume a role of passivity and acceptance of the limitations associated with that disease. According to Parsons, a state of disease is only acceptable if one is trying to get better. Remaining in a state of chronic disability was seen as a form of social deviance, as framed by Emile Durkheim, who coined the term social deviance as a way of differentiating between normal and pathological forms of social organization (Thomas, 2007). When disability is framed under the category of social deviance, not only are bodies seen as being deviant, but their participation in mainstream society is also deviant. Cockerham (2004) explained Parsons' approach to the term social deviance as

any act or behaviour that violates social norms within a given social system.

Thus, deviant behaviour is not simply a variation from a statistical average.

Instead a pronouncement of deviant behaviour involves making a *social judgment* (original emphasis) about what is right or proper behaviour according to a social norm (pp. 142-143).

That definition leaves little doubt as to how individuals with disabilities were treated in terms of access and inclusion in the 1950's.

Related to the idea of social deviance is the concept of social stigma. In the 1960's, Goffman developed his concept of social stigma, and its application in terms of illness and disability (Susman, 1994). In Goffman's framework of social stigma, a person who is perceived as different in some negative way (i.e. evil, dangerous or not able) is "reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). Importantly, however, the stigma is a function of the relationship between the person perceived as different and the person applying the label of social stigma. That is to say that the labeler has not necessarily perceived a negative attribute about the person; rather, they hold the dominant position in the relationship, allowing them to label with impunity (Goffman). Within the framework of Goffman's stigma, individuals with disabilities are given a label that carries a stigma of deviancy along with it (Thomas, 2007). Goffman paid special attention to the process of labeling, an important concept in the field of disability activism, as well as feminism and other groups of activists. Goffman argued that for people who have a stigma, "fulfilling their social obligation is ... a burdensome and unfair reality of life for people who are culturally (not inherently) discredited, with profound significance for personal identity" (Thomas, p. 23). The burden is even more pronounced for those individuals for whom 'passing' (disguising or masking differences) is not possible. Goffman's notion came into wide use in the 1960's, and this was the first significant step towards the social oppression model of disability that most sociological theorists use today.

Much of the current terminology of CDT was born out of the social movements of the 1960's and 1970's. Similar to activists fighting for racial, gender and sexual equality, this time period marked a turning point with respect to rights for people with disabilities, as they protested inequalities and advocated for inclusive policies in government and in the private sector

(Shakespeare, 2008). Shakespeare posits that the disability movement benefited greatly from the civil rights and feminists movements going on at the same time, but that the real change that occurred in this time with reference to disability was the new perception of disability as a societal problem, and not an individual problem. This notion was the forerunner to the social model of disability; however, at this point the disability movement was mainly involved in activism, with little scholarship to support it.

According to Thomas (2007), the 1980's marked a turning point in the field of disability studies, primarily in academia rather than activism. During this time, there were many first-person accounts of disability within various fields of academia, the results of which were two-fold. First, it marked a shift in the types of activities in which the field of disability studies was involved. Previously, it was involved in political action and demonstrating, whereas by the 1980's, the effect was being felt in the academic world, as well. Second, individuals with disabilities started to write about their own experiences, and were not just relying on academics to capture their experiences of disability. Another important development during the 1980's is that the social model of disability came into wide use. This model places the blame for limited inclusion on societal, rather than impairment-based barriers (Thomas).

Thomas (2007) argued that the ideas and concepts that constitute the current field of critical disability studies (CDS) developed and became popular in the academic community in the 1980's and 1990's. Samaha (2007), however, claims that the basic concepts of disability studies, including the social model of disability, had been developed by the 1970's. There is also evidence of research and political activism by and on behalf of individuals with disabilities in the 1970's, particularly relevant in a post-war climate of rehabilitating Vietnam War veterans. While the exact time period of the origins of this field of study is a matter of debate, the

overarching theme of CDS is not. Thomas aptly summed up the main thrust of CDS when she stated that “sociologists in disability studies use a *social oppression* (original emphasis) paradigm: to be disabled, or be discursively constructed as ‘disabled,’ is to be subject to social oppression” (p. 4). Critical disability theorists, such as Watts and Erevelles (2004) argued that the social oppression they address cannot be separated from other types of social oppression, such as sexism, racism and homophobia that to this day remain rampant.

While the field of CDS is now relatively well established (Thomas, 2007), there remains significant gaps in acceptance and awareness of this field. For example, the *Oxford Dictionary of Critical Theory* does not include any entries related to medical sociology or disability studies. It does not include any definitions for disability, or an explanation of the social oppression model of disability. Other books on critical theory, such as *Critical Theory Now* (Morrow, 1991) also do not include any references to disability or the field of disability studies. There are many scholarly works that discuss CDT and empirical studies that explored the theories in action; however, those works are usually exclusively dedicated to CDT (Thomas). CDT has not been utilized in other fields to explain oppression and marginalization the way CDT scholars have used the scholarly work from race and gender studies, for example, to theorize in their own field (Thomas). A notable exception to this pattern is the field of aging, which medical sociologists relate to disability studies (Turner, 2004). The link between aging and disability is clear, as older adults tend to have more disabilities and chronic diseases; however, the goals and theories of aging research are not necessarily in line with those of CDT, and the connection is not always a useful one for the larger political project of disability studies. Nevertheless, researchers in disability studies developed a rich framework of concepts and ideas that are current in sociological discourse today, as well as relevant to the lived experiences of individuals with

various types of disabilities. In the next section I will explain what critical disability theorists mean when they use the term disability, and some of the practical implications of their definitions.

Key Concepts

Framing Disability

Critical disability theorists conceptualize physical and intellectual disabilities in the same fashion, arguing that people with both types of these disabilities face the same basic societal barriers that prevent them from full inclusion and participation (Devlin & Pothier, 2005). The *Oxford Dictionary of Sociology* (Scott & Marshall, 2009) defines disability as “a disadvantage that is caused for the physically impaired by particular forms of social organization. An impairment is a loss or lack of functioning, such as blindness, paralysis, or mental subnormality – which, unlike illness, is usually permanent” (p. 180). Physical disabilities are caused by impairments in the body, such as paralysis and blindness, while intellectual disabilities may not manifest with physical symptoms, but are caused by an inherent or acquired impairment in brain function. There are some types of conditions, such as cancer in remission, that do not fit neatly into either category; nevertheless, CDT still defines those conditions under the broad heading of disability, and argues that the project of CDS applies equally to those individuals as well. It remains tricky, however, to clearly delineate who is and who is not included under the heading disability, partly because there are many who do not wish to so identify, and also because many disabilities are invisible, to the extent that a casual meeting with someone may not give away his/her status (Devlin & Pothier). One of the tasks of critical disability theorists is to make the boundaries of disability more clear, for purposes of research and for use in government policy.

Government agencies often try to measure certain variables in a population in order to ascertain frequencies and distributions. Disability is one such parameter that has been measured with varying levels of accuracy.

McColl, James, Boyce and Shortt (2005) conducted a systematic review of Canadian statistical data on the prevalence of self-reported disability. Over a period of a few years of data, results ranged from six percent prevalence to 15% prevalence, depending on the types of questions that were asked. In their discussion, McColl, et al. pointed out the importance of a comprehensive theory of disability that can contribute by attempting to clarify important conceptual issues, such as what is disability, what are the best practices for its measurement, and where and how the government can improve in the delivery of important services for individuals with disabilities in Canada. McColl, et al. stated that a related task of disability theorists and activists is to combat the stigma associated with disability, so that people with various types of disabilities do not fear social and societal repercussions as a result of disclosing their status.

Zola (1993a) pointed out the importance of not taking the neutrality of scientific measuring tools for granted when measuring the prevalence of disability. Even the most seemingly objective measurements are grounded in dominant discourses and must be challenged if we are to achieve meaningful social change. Zola argued that if we look deeply into any science, we will find the social and political factors that play a role in determining what is commonly known as scientific knowledge. With this in mind, all topics must be approached carefully, and this is especially true of issues pertaining to disability, where social stigma is so entrenched.

Models of Disability in Contrast with Social Deviance

The biomedical model of disability has traditionally been the most common framework from which studies of disability are conducted (Thomas, 2010). The biomedical approach to disability holds that disability is pathology, meaning an individual struggle for those who suffer from impairments due to birth defects or damage sustained later in life (Crow, 1996). The idea of disability as a form of social deviance is the natural consequence to considering disability only in the sense of functional, biological limitations, and indeed, until the advent of the social model of disability, there was a tendency to treat disability as a form of deviance in government policy (Thomas, 2007).

More recently, scholars' view on disability has changed, and this has occurred alongside many improvements in the treatment of individuals with disabilities in the developed world. In the last 30 years, sociologists have criticized and problematized the medical model, instead focusing on the societal barriers that people with disabilities face, and this is now known as the social model of disability (Samaha, 2007). Although the advent of this model has reframed much of the discussion about disability, there are scholars who have written about the shortcomings of the social model, and possible alternatives that may account for those issues.

In recent years, the social model of disability has come under scrutiny for the role it plays in reinforcing the binary of able vs. disabled. Other models that take into account impacts of intersecting variables gained recognition, such as the economic model and understanding disability on a spectrum (Devlin & Pothier, 2005). Shakespeare (2008) argued that although the social model brought issues of access into public consciousness and helped to shape important government policy with respect to disability rights, the model itself is too undefined to be useful

much longer. He pointed out that the term ‘oppression,’ is left wholly undefined in the literature on disability, an important conceptual drawback of the model, as it is predicated on the oppression that society inflicts upon those with disabilities. Shakespeare offered the additional criticism that the social model ignores the impact of biological impairments on the lives of those with disabilities and places all the blame on a disabling society, and this is similar to Crow’s (1996) point about the social model. She stated that it is difficult for those with disabilities to come to terms with their limitations when they are told that society is their root cause.

Another important drawback to the social model is its simplicity. Shakespeare and Watson (2010) wrote that due to the simplicity of the social model, it has limited utility in academia; it is lacking in the theoretical complexity that is crucial for ideas that last. An additional weakness, according to Shakespeare and Watson, is that its origins are not from the sphere of academia and research, but from a group of white, heterosexual men with physical disabilities. As such, the social model represents a very narrow understanding of disability, and does not take into account intellectual disabilities, as well as disabilities experienced by women and ethnic minorities.

There are, however, important developments that have come about due to the social model of disability. One of the most pertinent is the changing definition of disability found in the World Health Organization (WHO, 2012). The WHO is increasingly aware of the importance of societal barriers to inclusion, as is reflected in their most recent definition of disability. The presence or absence of a disability is characterized as one factor in assessing the health of an individual, as opposed to being the defining feature of that person (McColl, et al., 2005). While this definition still includes aspects of diagnosis and pathology, it is a significant move towards mainstream adoption of the social model of disability. Critical disability theorists realize that

unless society opens up to the concept of social responsibility for disability, little progress is possible in terms of taking down barriers and advancing inclusion, the ultimate goal of CDS. In the next section, I will discuss how CDS has been used as a tool for social change in the developed world, an important aspect of CDS in my study.

Critical Disability Studies as a Tool for Social Change

CDS is from the same school of thought as all critical studies, owing its original conception to Marx and the Frankfurt School (Crotty, 1998). In formulating the concept of what would become critical theory, Marx is well known for calling the proletariat to action for the purpose of overthrowing the yoke of bourgeoisie oppression (Crotty). The various forms of critical theories, such as feminist theory, queer theory, and critical pedagogy, are all simultaneously theoretical frameworks to be utilized in conducting research, and political projects, whose goal is the betterment of society along their chosen parameters (Morrow, 1991).

CDT takes a clear and unequivocal political stance on the issues pertaining to disability in society, and actively lobbies for societal improvement for individuals with disabilities. Devlin and Pothier (2005) claimed that unlike other social action projects that are developed from tenets of various social theories, the political project of CDS was formulated from the bottom up. Instead of theorizing from a standpoint of academia and the “ivory tower” (p. 9), the problems that CDS addresses are those issues that individuals with disabilities face on a daily basis.

Thomas (2010) described the changes in the Disability Discrimination Act in the United Kingdom in 2005, and attributed the steps towards full inclusion to the lobbying efforts of the disability movement. The policy changes included a pledge to work towards full societal inclusion for individuals with disabilities, as well as financial support for initiatives that promote

independent living for that population (Thomas). Thomas made reference to an active lobby for people with disabilities made up of those people whom the policy would benefit. An important component of the political project of CDS is that it does not give a voice to people with disabilities by having non-disabled people speak on their behalf; rather CDT advocates for people with disabilities to speak on their own behalf, and to effect change on their own terms.

Canadian government policy with respect to the rights of individuals with disabilities has a complicated history. The original Canadian Charter of Rights and Freedoms, which became a part of the Canadian constitution in 1980, did not include any provisions to protect people with physical or intellectual disabilities from discrimination on the basis of the disability (McColl, et al., 2005). It was based on the Canadian Bill of Rights, drafted into law in 1960, which did not include any references to disability (McColl, et al.). The patriation of the Canada Act Bill in 1980, under Pierre Trudeau, was an ideal opportunity to bring to light the lack of protection for individuals with disabilities. Disability activist lobbied for this protection, and they were ultimately successful, although McColl, et al. cited a few examples of politicians who did not wish to include the provision, including the future prime minister, Jean Chretien. The Canadian Charter of Rights and Freedoms now includes protection for individuals with disabilities from discrimination on the basis of physical or intellectual disability.

By the early 1980's, the disability movement gained recognition, and, in Canada, there was at least one concrete step towards recognition of the inequalities faced by those with disabilities. In the 1990's and later, however, many critical disability scholars feel that the Canadian government backtracked on pledges they previously made concerning inclusion and equality, and that policy changes have been based on the medical model of disability, placing the responsibility on individuals and charities to promote inclusion (Rioux & Valentine, 2005).

There remains a significant political and social project ahead of critical disability scholars and activists. An important element of this project is the concept of citizenship. Rioux and Valentine argue that the difficulty in creating effective policy to promote an inclusive society is the lack of clarity of the idea of citizenship. Indeed, citizenship is a complex concept within the field of CDS. In the following section I will discuss its importance and examine whether critical disability scholars succeeded in bringing this issue into public consciousness through activism and political lobbying.

Citizenship and Personhood

Devlin and Pothier (2005) expanded on the concept of citizenship and dis-citizenship, defining citizenship as

The capacity to participate fully in all the institutions of society – not just those that fit the conventional definitions of the political, but also the social and cultural. This latter approach emphasizes that citizenship is not just an issue of an individual *status* it is also a *practice* that locates individuals in the larger community (pp. 1-2).

Thus, according to Devlin and Pothier, citizenship is a complex, multifaceted issue that encompasses more than a person's basic rights and freedoms as a citizen of a particular country. Citizenship denotes a level of participation and inclusion in society where individuals are not discriminated against on the basis of dis/ability, or any other variable. Devlin and Pothier differentiated between full citizenship and abstract promises of rights and freedoms. They claimed that although the liberal lobby in Canada has pushed through a number of important rights for people with disabilities, these rights fall short of true citizenship, as they do not address

many of the core problems faced by people with disabilities. From this concept of citizenship, Devlin and Pothier conceptualized their version of CDT, and they further explained that the most important task of CDS is to challenge the assumptions upon which our society is based, especially when they give rise to situations of inequality and powerlessness.

The concept of personhood is closely related to citizenship, in that both concepts take the ideals of equality and inclusion farther than getting inside the door, whether literally or metaphorically. Devlin and Pothier (2005) explained that personhood denotes not evaluating a person's worth based on his/her potential economic contributions to society, or on his/her gender or race, but actually seeing him/her as a person, and treating him/her with the appropriate respect. In this model, individuals with disabilities are not to be treated as charity cases, or as people to be pitied due to their poor lot in life. If it happens that a person needs some kind of accommodation due to a disability, he/she should not be made to feel different or excluded because of that small detail. Using personhood as the ideal can be a useful way to avoid binaries, such as disabled and non-disabled, because in this ideal, everyone is to be treated as a person, and not as a set of biological functions. Devlin and Pothier wrote at length about the need to eliminate the "hierarchy of difference" (p. 12) that currently exists between disabled and non-disabled people, as well as between different types of disabilities. They argued that by placing certain types of people over other types in a hierarchical fashion, societal oppression is perpetuated, whether the hierarchy is conscious or below the surface.

Williams (2010) expanded further on the notion of personhood, and explained that individuals with chronic illnesses and disabilities often fall into the trap of thinking of themselves in biological, functional terms. Williams described a person who has diabetes who thinks of him/herself in terms of glucose levels, instead of meaningful human variables.

Williams theorized about an idea of biological citizenship, in which the responsibilities that one perceives as a citizen of one's country, province or city are seen through a lens of medical terminology and diagnosis. Williams advocated for a holistic approach to personhood and citizenship, one that avoids fragmenting people into medical selves and social selves. Related to these concepts are those of inclusion and exclusion based on biological parameters, issues that are closely linked with language and communication.

Language Issues

Devlin and Pothier (2005) pointed out the importance of inclusive language in dealing with issues of inclusion and exclusion in society. Jager (2001) stated emphatically that discourse is what drives knowledge in society, and that language is one of the most important sources of discursive information that we encounter. Jager claimed that discourses lend structure to society by giving people the basic information and ideas by which they form attitudes. Language is a prime mechanism of inclusion and exclusion in a number of different fields of study. Gender-inclusive language is an important consideration in any kind of writing, and it is a consideration that has become a part of government policy and academic writing. Issues of inclusive language in the realm of CDS are not as clear-cut. The common use of verbs such as walking, to denote going somewhere, or running, with the intended meaning of rushing somewhere, are commonplace in all kinds of writing, as well as in everyday conversation (Thomas, 2010). Critical disability scholars insist that this kind of language reinforces the discourse of ableism that permeates society, and works to symbolically exclude individuals with disabilities from mainstream avenues of communication.

Another area of CDS in which the issue of language is important is in deciding how to refer to individuals with disabilities. Zola (1993b) pointed out the issue of self-identification among those with disabilities. Due to the lack of an identifiable sub-culture in this population, issues of labeling take place on an individual level, instead of an a community level, as is the case with gender and ethnicity (Zola). Zola spoke out against the use of passive language, which is common in medical terminology, to describe those with disabilities. There is a world of difference, Zola argued, between one who is “confined to a wheelchair” (p. 70), and one who is a “wheelchair user” (p. 70). Similarly, he noted the symbolic difference in language between a person who *has* a disability and a person who *is* disabled. Importantly, Zola emphasized that he was not commenting from a framework of political correctness; rather, he holds that there are real consequences to using language that disables. After the passage of the Americans with Disabilities Act in 1990, scholars began to explore the concept of labeling and definition among those with disabilities, and documented the activist movement that was trying to bring issues of language into public consciousness (Haller, Dorries & Rahn, 2006). Haller, et al. came to the conclusion that the use of disabling language, in media and research can have negative effects on the perceptions the readers have of disability. Therefore, in my study I am using active, rather than passive language, such as individuals with physical disabilities, as opposed to disabled people.

There has been considerable progress made in the area of inclusive language in the academic community, but it remains unclear if CDS has been successful in bringing this awareness to public consciousness as of yet. The final research focus to discuss in this review of CDS involves the research on the intersection of CDS and physical activity. Issues of bodily identity are also important in discussing this topic.

Active Bodies with Disabilities

Erevelles (2000) pointed out that in discussing various forms of embodiment in the literature on education, there is a conspicuous lack of reference to the disabled body. The literature on physical activity and disability focuses, almost exclusively, on the functional limitations caused by disability, and focuses on barriers and facilitators with respect to participation (Rimmer, et al., 2004). There is little material from a sociological point of view, on the physical activity behaviours of those with disabilities. There is a peer-reviewed journal on physical activity for those with disabilities, *Adapted Physical Activity Quarterly*, but the vast majority of articles found there describe quantitative outcome measures of physical activity, and quantitative assessments of current adapted physical activity programs. Little attention is paid to the qualitative experiences of those with disabilities who participate in physical activity.

Allender, Cowburn and Foster (2006) conducted a review of qualitative studies on physical activity among various populations. They found that men with physical disabilities lacked knowledge and confidence with respect to physical activity, and were reluctant to engage in exercise. They also cited lack of positive role models as a reason for lack of motivation.

The concept of active disabled bodies is important in CDS, though it is not sufficiently researched at the moment. There are some difficulties in obtaining information on this topic, including the obtrusiveness of data collection for an already over-studied population (Martin Ginis & Hicks, 2005). The most significant barrier to relevant information on this topic, however, is dominant discourse that discourages inquiring too much into the physical lives of those with disabilities. Any such inquiry necessarily touches on barriers and other issues that prevent participation. The liberal society in which we reside likes to minimize, as much as

possible, the perception that there are any barriers in society based on ability (Devlin & Pothier, 2005), and people are loathe to abandon such comfortable misconceptions. Further research is certainly needed in order to understand not just the physical barriers to participation among those with disabilities, but also the sociological and discursive barriers that prevent full inclusion and participation among this segment of the population.

My proposed research study will fill in this crucial gap in the literature with respect to the social and discursive barriers to physical activity participation among those with physical disabilities. CDS is the appropriate theoretical framework to utilize in the analysis of social barriers for those with disabilities, due to its adherence to the social model of disability, as well as its emancipatory goals for those with disabilities. In keeping with the larger framework of critical theory, I will also consider using a gender-based analysis (GBA) when examining findings, as I have identified a trend in the literature whereby males with disabilities have greater rates of physical activity participation than females (Crawford, Hollingsworth, Morgan & Gray, 2008), and this trend is not adequately explained.

Methodology

The methodology for my MA thesis is discourse analysis. I chose this methodology because it employs the epistemology of social constructionism (Phillips & Hardy, 2002), which is the prevailing epistemological stance in the study of physical disability. In this section of my proposal, I will briefly explain what the term discourse means, why it is a vital part of our social reality, and most importantly, the relevance of discourse analysis to my study.

Discourses consist of “the flow of knowledge” (Jager, 2001, p. 34) that informs the actions and attitudes of individuals and societies, and they exercise power through the underlying

structure they lend to society. Jager claimed that even when a researcher is attempting to critically analyze discourse, he/she is trapped inside the dominant discourse, and will reflect elements of that discourse in the analysis. The researcher must exercise reflexivity in order to properly carry out a critical analysis of the relevant discourses. The discourses relevant to my proposed thesis are connected with constructions of the body, bodies with physical disabilities, and discourses about disability in general. I am an individual with a physical disability, and in utilizing discourse analysis it is important to realize how I am a product of the dominant discourses I seek to analyze. One can view this aspect of discourse analysis as a disadvantage, but discourse is at work in every possible type of research, and by exercising reflexivity and keeping in mind this important complexity, the potential contribution of research that utilizes discourse analysis is enhanced and not weakened.

Discourse analysis has traditionally been a methodology used in linguistics to analyze words and the role of language in society (Potter, 2008). Since the 1980's, it has been utilized in a number of other disciplines, including sociology of sport and physical activity (Eskes, Duncan & Miller, 1998). There are a number of offshoots of discourse analysis, including Foucauldian discourse analysis and critical discourse analysis (CDA) (Weninger, 2008). The main focus of discourse analysis is the deconstruction of statements and basic knowledge in society that is usually taken for granted (Phillips & Hardy, 2002). In doing so, we can discover why we think and act in certain ways, and understand how prevailing discourses can be oppressive or restrictive to certain groups in society. Discourse analysis is relevant to my proposed research topic of societal barriers to physical activity for people with physical disabilities because of the discourses and social constructions surrounding bodies and disability in society. There are powerful discursive conceptions of the body, and more importantly for my proposed research,

the active sporting body. For example, Inahara (2009) pointed out the discourse of ableness that permeates the realm of embodiment and physical activity. Discourse analysis provides the researcher an opportunity to look more deeply at this discourse and the social construction of bodies in general. Additionally, through the use of CDA, there is an opportunity to analyze these discourses using a critical lens, an important component of research on marginalized populations, including those with physical disabilities.

Grue (2011) pointed out that very few studies dealing with disability have used CDA as part of the methodology, and listed a few reasons why it is an appropriate choice of methodology for studying the disabled population. Firstly, people with disabilities are an identifiable segment of the population, that like women, homosexuals and people of different races, has traditionally been marginalized and silenced. CDA aims to give voice to the issues facing marginalized populations such as these, making it an appropriate tool for both research and social change. Secondly, the field of CDS has been criticized for its insularity and adherence to traditional forms of data analysis. In order to gain ground in the competitive academic arena, it is crucial for CDS scholars to branch out into different methodologies and create lines of communication into different fields. Thirdly, CDA seeks to problematize and demystify common sense notions of reality, ultimately replacing them with more equitable, though often more uncomfortable truths (Fairclough, 2003). For too long, the medical model of disability has been given free reign in research circles, despite advances in the scholarly work of CDS, and the dissemination of the social model of disability is a project well-suited and in line with the goals of CDA (Grue).

Weninger (2008) argued that the use of CDA is appropriate when analyzing literature distributed by government organizations and media texts, both of which are relevant sources of information for my research. Weninger further explained that due to CDA's social

constructionist epistemology, it is an appropriate methodology to utilize when attempting to deconstruct notions of what is normal and acceptable in society. Discourses of normalcy are largely built on government policy, in addition to the societal attitudes out of which they are conceived (Fairclough, 2001). CDA is a useful methodology for deconstructing these messages and commenting on their implications for society, specifically with respect to those segments of the population that are consistently marginalized. Kang (2009) utilized CDA to deconstruct disability from the standpoint of a teacher she studied. In her paper, Kang argued that the medical model largely informs the discourse surrounding disability, but that these discourses can change over time as a function of better education and better research to inform that education. Kang's example is important, as she utilized the method in a fashion that moved beyond linguistic analysis of discourse to analyzing larger concepts that are held as truth in society today; moreover, she did this by analyzing a marginalized group, children with disabilities, an important component of critical research that is also accounted for in my proposed study.

Similarly, a number of scholars have used CDA to deconstruct notions of the body among the disabled and non-disabled alike. For example, Siebers (2001) explained that the disabled body presents a challenge to avenues of popular representation, because of the lack of clarity with respect to how to represent the disabled body. He argued that this is due to dominant discourses of the body that do not allow deviation from the norm. Another example of an author who incorporated discourse analysis into the study of bodily construction is Inahara (2009), who tied in notions of femininity, disability and bodily construction to try to deconstruct and problematize the dominant discourse of ableism. The critical component of discourse analysis is not only expressed by the choice of topic or population segment to be studied, but also in the problematization of discourse (Phillips & Hardy, 2002). Problematization is an important tenet of

critical theory, and it is a means by which critical research differentiates itself from descriptive or exploratory research (Crotty, 1998). Problematization is an important methodological component of my proposed study, as the discourses encountered when discussing physical disability and physical activity participation remain problematic in society today; a simple description of those discourses would be insufficient and redundant. Through problematization, the researcher can make novel insights regarding the discourse in question, and it becomes possible to break through entrenched attitudes to begin the process of shifting discourse towards less oppressive attitudes (Jager, 2001).

One of the complexities of CDA, and discourse analysis in general, is the opposition faced by those who wish to challenge the status quo (Fairclough, 2001). The concept of discourse posits the existence of a constructed reality from which individuals in society are not able to break free; as such, the concept of discourse in and of itself is not neutral. There are those in society who find it problematic, mainly those in positions of authority who stand to lose out if their authority is challenged (Fairclough). The challenge for scholars who use discourse analysis often consists of espousing views and problematizing issues that others would rather not be mentioned. While this issue presents a barrier to the use of discourse analysis, it is also perhaps, the most important component of this methodology in that it seeks to bring attention to difficult subjects. Additionally, discourse analysis seeks to apply theoretical concepts to practical situations, often where policy makers may not want the issue deconstructed and problematized. The use of small samples, a common feature of discourses analysis, presents another issue when trying to translate research findings into policy, as more robust statistical results involving large samples are often preferred.

Methods

Discourse analysis lends itself to a number of research methods. Among the many options, I will use an environmental scan of relevant resources and interviews to conduct my research. The environmental scan is relevant because of the information readily available through government sponsored outlets can provide with respect to government policy in connection with physical activity and health resources in Canada. Interviews are important in order to obtain information from individuals involved in the development and writing of those resources, as well as from end-users with physical disabilities, to obtain their opinions on current resources, and where they are lacking. In the following section, I will outline the benefits and drawbacks of these research methods, and highlight the importance of these methods in undertaking my study.

Hatch and Pearson (1998) described environmental scanning as a method of gathering information from available resources in an unobtrusive manner. The source of this information is important, as documents created as a part of government sponsored initiatives are authoritative in the sense that they speak to the goals and sensitivities of that government (Caseñas & Kalsbeek, 2006). Those documents scanned speak for individuals and groups in society that hold some measure of authority over public policy and its associated published materials. The documents I am planning to analyze include Federal Disability Reports over the past several years that have outlined the gains made in the inclusion of people with disabilities in Canada, as well as the issues yet to be addressed, and promotional materials for physical activity and health developed and disseminated in the same time period. These documents are rich sources of dominant discourse with respect to embodiment and ability. The inclusion or exclusion of those with disabilities is an important point of analysis.

Environmental scanning complements CDA, because these documents do not provide a comprehensive picture of societal issues and context, primarily due to their nature and authorship (Murphy & Dingwall, 2003). Present in abundance, however, are key points concerning what discourses are at work in the formation of public policy, and what the voices of authority say on those discursive issues. Building on Jager's (2001) definition of discourse as "the flow of knowledge" (p. 34), documents created through government funding are an excellent source of this taken for granted knowledge. Accordingly, CDA is an appropriate methodology with which to approach this information, because in doing so, it can be analyzed and problematized to challenge those discourses.

To complement my environmental scan, I conducted interviews with individuals involved in the development and ongoing revision of the Canadian physical activity guidelines, as well as individuals involved in initiatives to promote physical activity among people with physical disabilities. Four interviews were conducted from this group.

I conducted a second set of interviews with individuals who have physical disabilities, in order to gain insight into their perspectives on physical activity participation, knowledge and resources. In keeping with other studies that employed various research methodologies in the study of disability (Kang, 2009; Hardin, 2009), I interviewed four individuals with physical disabilities. I recruited individuals with physical disabilities with varying levels of involvement in physical activity in order to explore some of the social barriers each individual faces in accessing physical activity resource and participation. All of the participants from this group were recruited from a private physiotherapy clinic in Toronto.

I used semi-structured interviews, as certain questions can be answered in a straightforward manner, but others required elaboration on my part and the subjects' in order to

obtain pertinent information. One of the benefits of using semi-structured interviews in a research setting is that the research can probe for interviewee for information, including important contextual details and issues the researcher might not be aware of from the outset of the project (Murphy & Dingwall, 2003). Information of this nature can only be obtained through dialogue, and interviews provide an appropriate setting for this dialogue to take place.

Overall, I conducted eight interviews, each interview lasting 40-60 minutes. The interviews took place at locations convenient to the subjects, and were scheduled at their convenience. Interviews were recorded using a digital recording device, and transcribed manually. Transcripts are stored in a locked office of thesis supervisor, Dr. Eileen O'Connor, University of Ottawa. In order to guarantee the anonymity of the research subjects, pseudonyms are used, and any remarks that could be used to identify the subject are not used in the thesis. Transcripts were coded manually using the structure of data analysis described by Norman Fairclough (2003). By using this mode of analysis I was able to relate the data set back to the dominant discourses I identified in the literature, as well as explore discourses not previously identified.

In summary, by using CDS in conjunction with critical discourse analysis, I have been able to identify and critique dominant discourses with respect to people with physical disabilities found in PA promotional materials and interviews with study participants. The overall goal of this project is to fill the gap in our current understanding of the social barriers to PA for those with physical disabilities, and to suggest possible avenues for remedying this situation.

Thesis Outline

Chapter one of my thesis consists of an introduction to the topic of study, an overview of the relevant literature, theoretical framework, and methodological framework. The literature review is organized in three sections: the first is a review of current physical activity guidelines and materials in Canada and elsewhere in the developed world; the second is the impact of the exclusion of those with physical disabilities from those materials; and the third section will address strategies identified in the literature to address this exclusion. This section will be followed by the theoretical framework in which my research is situated, critical disability studies, as well as the methodology, critical discourse analysis. Following the first chapter, the second chapter, my first article manuscript, will consist of an analysis of the perspectives of end-users with physical disabilities regarding the current PA guidelines available to them, and where they feel improvements can be made. The second article manuscript in the third chapter will be a discourse analysis of interviews with individuals involved in the development of the above-mentioned resources, and the delivery of PA promotion services to people with disabilities. Chapter four will consist of a general discussion and conclusion of both article manuscripts. The appendices will include the ethics application, interview guides and promotional materials analyzed.

Chapter II

Knowledge and Attitudes of Current Physical Activity Guidelines Among a Sample of Canadians with Physical Disabilities

Abstract

Physical inactivity patterns among people with physical disabilities have been well documented over the past number of years. Many studies have identified physical and psychological barriers to participation that affect this segment of the population with respect to their access to physical activity facilities, and readiness to participate in those programs that are available. The barriers inherent in government policy and spending on physical activity guidelines and resources have not been well studied. An exploration of the discourses that contribute to the routine exclusion of people with disabilities from health promotion literature in Canada is key for remedying the issue of physical inactivity that impacts not only health, but quality of life for more than one in ten Canadians. Four participants, recruited from a private physiotherapy clinic in Toronto, with physical disabilities were interviewed regarding their own physical activity participation, their use of available PA resources, and their thoughts on disability in Canadian society. Using critical discourse analysis, the transcripts were analyzed to identify dominant discourses that shape both their experiences and actions with respect to PA participation. The analysis reveals that notions of the medical model of disability hold a prominent place in how the participants view themselves and their opportunities to participate in physical activity. The need for an effective lobbying group with which to effect change came out strongly as a potential solution to this issue.

Key Words: Physical Disability, Health Promotion, Discourse, Medical Model, Social Model,
Critical Disability Studies

Introduction

Physical inactivity has been identified as a national concern in Canada, due to the short and long-term consequences of a sedentary lifestyle and high BMI (Warburton, Whitney Nicol & Bredin, 2006). While Martin Ginis and Hicks (2007) report that 35% of Canadians without disabilities are physically inactive, the situation for those with physical disabilities is even more serious, with 56% of people with physical disabilities classified as inactive. According to 2006 Statistics Canada data, the incidence of disability in Canada is fifteen percent. Twelve percent of the Canadian population reports a disability related to mobility (Statistics Canada) This segment of the population reports poor access to transportation, employment and health services (Human Resources and Skills Development Canada, 2010) Although Canada has made progress in the areas of full inclusion and accessibility for those with physical disabilities, especially in terms of accessibility policy on the provincial level, there remains distinct and significant areas for improvement. One of these areas is physical activity. People with physical disabilities, including those with spinal cord injury, are one of the least active segments of the population (Martin Ginis & Hicks, 2005). Despite the wealth of evidence regarding the benefits of physical activity (Pate, et al., 1995, Warburton, et al.), there have been no evidence-based guidelines for physical activity for people with physical disabilities until very recently (SCI Action Canada, 2011). The potential implications of physical inactivity for those with physical disabilities includes increased risk for chronic diseases, such as heart disease, obesity and type two diabetes (Martin Ginis, Latimer, Hicks & Craven, 2005). Hence, a solution to the issue of poor access to physical activity and the overall poor health reported by people with physical disabilities is both a pressing social, and long-term population health concern.

This paper examines several barriers Canadians with physical disabilities face with regard to physical activity opportunities. The paper will also explore issues relating to the provision and dissemination of physical activity guidelines and promotional material directed towards this population. Key areas of focus in this analysis will include the place of people with physical disabilities in Canadian society, the contested definition of disability, and what physical activity means to the study participants.

An important issue identified by Martin Ginis and Hicks (2007) is how disability is defined in the academic literature associated with the Canadian Physical Activity Guidelines along the lines of the medical model of disability. The medical model of disability focuses on physical impairment as the root cause of disability and any associated exclusion. This model excludes societal barriers that hinder participation (Barnes & Mercer, 1996). Martin Ginis and Hicks posited that to this point, people with physical disabilities have been seen as beyond the reach of health promotion efforts due to their physical impairments, and no efforts have been made to move past that perception. While a lot of important research had been conducted regarding the barriers people with physical disabilities face in accessing and participating in physical activity, the research has been grounded in the medical model of disability (Rimmer, 2005). Although there are some references to mobility aids in the Canadian Physical Activity Guidelines, no reference is made to the unique social, psychological, and policy-related barriers they face, no other examples of adapted sports and physical activity are provided, apart from wheeling. Additionally, the process of creating the guidelines has not included people with physical disabilities (Sharratt & Hearst, 2007), and does not provide evidence-based recommendations on the amount and type of physical activity that should be performed by people with various physical disabilities in order to improve health and avoid chronic diseases.

Consequently, people with physical disabilities do not have access to information regarding the specific health benefits of physical activity that are applicable to them, as well as the risks of remaining inactive. The only exception to this is adults with spinal cord injury, who can use the newly established physical activity guidelines for adults with spinal cord injuries to access this crucial information on improving their health (SCI Action Canada, 2011).

In the growing field of critical disability studies, research is informed by the social model of disability that has been posited by disability studies academics since the 1970's (Shakespeare, 2008). The main argument of the social model of disability is that societal barriers, and not physical impairment, are the root causes of the issues surrounding disability including the exclusion from many spheres of life (Barnes & Mercer, 1996). Although there are valid criticisms of the social model of disability (Crow, 1996), the focus on applied research and advocacy by and on behalf of those with disabilities that is emphasized by this model guarantees its relevance and currency. Thus, in this study, I will highlight important theoretical aspects of the definition of disability as identified by study participants in an attempt to better understand how each end-user conceptualizes disability.

The purpose of this study is to gather detailed perspectives on current PA guideline material in Canada from people who currently have physical disabilities in order to comment on where the current resources are adequate, and more often where they do not meet the needs of this population. Special attention will be paid to the role of discourse in the lives of people with physical disabilities, in order to problematize many of the commonly accepted notions related to disability and health promotion. Future directions in the development and dissemination of health promotion resources will also be discussed, as relevant to the viewpoints of the end-users.

The issue at stake here is not just the somewhat abstract value of inclusion and equality; rather, the quality of life for 15% of the Canadian population (Statistics Canada, 2006). Individuals with physical disabilities report more ill health and less life satisfaction than those who do not identify as having a physical disability, and they report much less physical activity (Martin Ginis & Hicks, 2007). It is important that policy makers and researchers take note of possible solutions to this problem of low PA levels among people with physical disabilities, and continue to focus attention on including this population in the wider discourse on health and health promotion.

Method

This study used qualitative methods in order to examine in detail the discourses that help shape decisions made by those with physical disabilities about physical activity participation. Data was analyzed using Fairclough's (2003) critical discourse analysis (CDA) protocol for analyzing texts. The advantage of this approach is that it is geared towards analyzing and problematizing dominant societal discourses, rather than just describing the status quo (Van Dijk, 2009). Like many qualitative methods, CDA is built on the foundation of critical theory, and its practitioners have clear political goals in mind (Wodak & Meyer, 2009). Further built on the area of critical linguistics, CDA requires an in-depth analysis of texts that explores the words and underlying perspectives of those under study (Fairclough).

Participants

This study took place in the winter of 2012 after obtaining ethics approval from the Research Ethics Board at the University of Ottawa. Four participants were recruited from a

private physical therapy clinic in Toronto, Canada. All participants self-identified as having a physical disability related to mobility, requiring the use of mobility aid. The participants spanned a large age group, from early 20's to 60's, and were both male and female. In this group, there were participants who lived their entire lives with some kind of physical disability, and others who acquired a physical disability later in life. Interviews were conducted in English, the first language of both the interviewer and interviewees.

Criteria for participation included self-identification as having a physical disability, fluency in English, and having achieved the age of 18. Informed consent was obtained from each participant before the start of his or her interview. The participation of each participant consisted of one interview, conducted by the principal investigator. The interviews were conducted at the physical therapy clinic from which they had been recruited.

The same interview protocol was administered to each of the subjects. The principal investigator developed the interview guide after reviewing the literature on physical activity for people with physical disabilities in Canada and throughout the developed world. The short-form PARA-SCI was administered along with the interview questions in order to measure current physical activity participation among the study participants. The PARA-SCI is a validated physical activity measure for people who have spinal cord injuries or who use mobility aids in their day-to-day lives (Martin Ginis, et al., 2005). It uses standard definitions for levels of intensity and has standardized prompts to facilitate accurate recall of all physical activities performed over a three-day period.

Each study participant was interviewed one time, with the interview lasting from 40-60 minutes. The interview guide dealt with topics such as the role of physical activity in their lives, how participants access information on physical activity, identify barriers they face in

incorporating physical activity into their lives, as well as the broad issue of physical disability in Canadian society.

All interviews were digitally recorded and transcribed by the principal investigator. Interview transcriptions were returned to the participants by e-mail for their review and revisions. Study participants in their review made few revisions, and the revised versions of the transcripts were used in the data analysis process. End-users will remain anonymous in this report. All names have been changed.

Data Analysis

Critical discourse analysis (CDA) is not only a method of analyzing text, but also suggests an approach to text itself and the underlying discourses in which it is grounded (Fairclough, 2003). When using CDA to analyze any type of text, the researcher does not remove their own views of the research question under study; rather, the use of CDA serves to problematize and counter the dominant discourses encountered in the texts, consistent with the critical theory basis of CDA. Additionally, the researcher acknowledges the various outside influences that may affect her data analysis and interpretation, such as the larger body of scholarly and activist work that comprises the field of critical disability studies, the commonalities she shares with many of her research participants, and the sociocultural setting in which the data collection and analysis took place.

Identical data analysis methods were used for each interview transcript. Transcripts were analyzed and coded according to Fairclough's (2003) framework for analyzing texts, a method that focuses both on the linguistic aspects of what was said, as well as identifying and analyzing the discourses referenced in each text. A table depicting the major points of analysis is shown

below. Some points of analysis ask the researcher to gauge the text as a whole along certain parameters. In those cases, it should be noted, the researcher made the decisions at her own discretion, based not just on the transcription, but notes taken during the interviews that remarked non-verbal gestures, tone of voice, sarcasm, and other pertinent details.

Table 1

Data Analysis Method

Category	Example of Question	Examples
Social events	What social event is the text a part of?	Physical activity, sporting match
Genre	What genres does the text draw upon?	Interview, government document
Difference	Characterize the orientation to difference in the text	Exploration of difference, accentuation of difference, focus on commonality
Assumptions	What is the implicit meaning of the text?	Existential, propositional, value
Discourses	What discourses are drawn upon in the text?	Medical model of disability, exclusion of people with disabilities, responsibility, health, quality of life, citizenship, inclusion
Styles	What styles are drawn upon in the text?	Way of acting – assertive, passive
Modality	What do authors commit themselves to in terms of truth (epistemic modalities), or in terms of obligation and necessity (deontic modalities)?	May, maybe, could be, probably
Evaluation	To what values (in terms of what is desirable or undesirable) to authors commit themselves?	I agree, good idea, that makes sense

Categories consisting of discourses, as well as theoretical and practical themes were identified from the interview transcriptions using manual coding techniques. Separate lists of categories were constructed for each interview, and then lists were compared to one another for similarities and differences. A list of common themes was constructed, as depicted in the table

below. The decision as to which themes would be chosen for further analysis in this paper was based upon how consistently the theme was referenced throughout the interviews, as well as its relevance in critical disability and health promotion literature.

Table 2

End-User Categories/Themes

Category/Theme	Example from Interview
Medical definition of disability	“How I define it, some kind of physical impairment that negatively impacts your day-to-day living and function.”
Exclusion from PA guides	“I would not look for resources directed to anyone in the general population, because a lot of those activities I can’t do.”
Rehabilitation	“I think ultimately their (people with physical disabilities’) physios will be the ones to give them the best suggestions.”
Expectations for improvement	“Setting up an effective group with which to lobby, but you need to first establish a focus.”
Barriers to PA participation	“I have in the past found a very long wait get onto the Lyndhurst (rehab gym) roster for exercises in the fitness program.”
Where to look for PA resources	“I would want to find an organization or an individual that would be able to provide information specifically on exercises for spinal cord injuries.”
Perception of people with disabilities	“I have personally found that once you’re in a chair ... that you become below the sideline. ... I think that in many respects we don’t exist for many people.”

Herein describes the participants who accepted to participate in my study.

Judy is 21 and has lived with a physical disability for her whole life. Born with circulation issues affecting her lower right extremity, she uses a scooter or two canes to get around. This participant reported no other physical issues at the time of the interview. Judy has an active lifestyle due mainly to the intensive physical therapy regime she maintains.

Melanie was 19 when she sustained a spinal cord injury, and she has been living as a paraplegic for 23 years, using a manual wheelchair. She maintains an active lifestyle both in terms of physical activity and advocacy in the disabled community. In her career, she has

assisted people with various physical disabilities adopt healthier behaviours and try out various wheelchair sports.

Sharon was first injured in her late teens, and has dealt with various secondary complications and additional surgeries over the past 30 years. She uses a power wheelchair outside the house, and walker when at home. She has a difficult time completing activities of daily living, leaving little energy for leisure time physical activity.

Nicole is an amputee, having sustained a lower body injury as a child. She is a member of a rehabilitation-based gym where she exercises once a week.

Findings – Theoretical themes

The findings in this paper are organized according to theoretical and practical issues that were identified in the data analysis. Theoretical themes that will be discussed are the contested definition of disability, the place of people with physical disabilities in Canadian society, and what physical activity means to the study participants. The practical concerns raised relate to what type of health promotion resources are currently available, what the study participants would like to see in the future, and where the responsibility lies with respect to the provision and dissemination of such materials.

Participants were asked to define disability and comment on potential issues that relate to disability. Participants were free to come up with their own ideas of what physical disability meant to them. At that point in the interview, no definition or opinion on the concept of physical disability had been offered. The tables below provide examples of the definitions study participants offered of disability, as well as definitions of disability from the critical disability studies literature.

Table 3

Definitions of Disability

Participant	Definition
Sharon	“A restriction that prevents ... certain parts of the body from functioning to their utmost ability.”
Nicole	“I would define physical disability as the limitation of parts of the body which were once able to function or once accessible, or in the general population would be accessible.”
Judy	“I don’t like the word disability because I feel that everyone has so many abilities, but I guess to me a physical disability is something that is visible on the outside I guess, somebody who requires the use of maybe walking aids, or a wheelchair, or braces. That to me is the physical and it limits them in some form of mobility.”
Melanie	“How I define it, some kind of physical impairment that negatively impacts your day-to-day living and function.”

Model	Definition
Medical	“The notion that a person with a disability has been inflicted with a personal tragedy” (Donoghue, 2003, p. 201). “The assumption that the individual is ‘disabled’ by their impairment” (Barnes & Mercer, 1997, p. 1).
Social	“Is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Oliver, 1996, p. 31). “Explores how socially constructed barriers (for example, in the design of buildings, modes of transport and communication, and discriminatory attitudes) have ‘disabled’ people with a perceived impairment (Barnes & Mercer, 1997, p.1).

All four of the participants defined disability mostly in terms of impairment and limitation. While Judy was hesitant to put a label on exactly what disability means to her, “because I feel that everyone has so many abilities,” she, too, settled on the concept of limitation as the marker of what disability means in a practical sense. Sharon mentioned the idea that disability is a condition that limits the use of the body to some extent, though it is a vastly

different experience for each person, and Nicole similarly described disability as existing within the body, limiting the body or some of its parts in terms of their function. Melanie summed up her notion of disability as “some kind of physical impairment that negatively impacts your day-to-day living and function.”

The contested discourse of dis/ability came out strongly in the interviews with the study participants, as is evident in their responses displayed in Table 3. Although critical disability scholars argue for the currency and relevance of the social model of disability, which describes disability as an issue of social and economic inequality that permeates society (Thomas, 2007), the biomedical model of disability, which describes disability as a pathology that exists within an individual (Shakespeare, 2008), was the discourse that was most strongly expressed by all the participants. While participants acknowledged the potential use for the social model of disability, they were largely unfamiliar with the concept of social inequality as a basis for defining disability. Among those I interviewed, there is a perception that physical disability is a personal experience, characterized by specific physical impairments. This is in line with the dominant social discourse of disability, which describes it as something that resides within an individual, placing the onus of responsibility on that person to deal with the various issues that may come up as a result of their impairment (Brisenden, 1986).

I found an overall perception among the study participants that people with physical disabilities are perceived differently in Canadian society than are people who do not have obvious or apparent disabilities. The result is a feeling of exclusion among the study participants, a concept related to disability that has been identified by a number of critical disability scholars (Shakespeare, 2008; Thomas, 2007; Crow, 1996), wherein individuals with disabilities do not feel as though they are full participants in society. My study revealed a range of experiences,

including feelings of exclusion, but also feelings of inclusion. Sharon characterized the feeling she experiences as that of being a “non-entity in some respects” to those with whom she interacts, and she feels as though she “doesn’t exist” for many people she comes across in her daily activities. Sharon reported that even at fitness facilities that are designed to specifically cater to the needs of those with physical disabilities, she felt as though the staff was uninterested in helping her, and she was still unable to use a lot of the exercise equipment without some form of assistance. Judy, on the other hand, is not even comfortable approaching a specially designed fitness facility, and is more comfortable engaging in physical activity through her physical therapist and at home. Melanie emphasized that she is willing to go out and try anything; indeed she has been active in getting other people with disabilities involved in adapted sports and physical activity. The lack of accessible facilities, however, forces her to exercise at home, an option not open to all people with disabilities due to both financial and knowledge related barriers (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004).

Devlin and Pothier (2005) described this issue of exclusion and lack of societal participation as the issue of citizenship. They defined citizenship as

The capacity to participate fully in all the institutions of society – not just those that fit the conventional definitions of the political, but also the social and cultural. This latter approach emphasizes that citizenship is not just an issue of an individual *status* it is also a *practice* that locates individuals in the larger community (pp. 1-2).

Those interviewed clearly stated their opinion that the ideal of full citizenship has not yet been reached in Canadian society. Apart from the physical barriers to public spaces that I will touch

on in the following section, there is an overall feeling of exclusion in various aspects of daily life that those without disabilities experience, such as access to employment, public spaces and physical activity.

During the interviews, I tried to get a sense of what physical activity means to the study participants. I found that the participants view physical activity not only as a healthy lifestyle practice, but also as a tool for developing the capacity to engage in normal daily activities without pain and other limitations. Melanie also touched upon the issue of “functional independence,” where physical activity affords her the opportunity to live more independently than if she did not have an active lifestyle. While all participants reported some physical activity participation over a three-day period on the PARA-SCI measuring tool administered during the interview, they all acknowledged various barriers herein discussed that kept them from achieving the level of participation they desired.

One of the issues that figured prominently in the participants’ discussion of their physical activity participation was exclusion from many avenues of participating; a discourse well documented in the literature both on physical activity (Rimmer, et al., 2004) and critical disability studies (Devlin & Pothier, 2005). The lack of physical access to physical activity facilities was an important aspect of this exclusion, but it also extended to attitudinal barriers both on the part of fitness professionals and the participants themselves, with respect to their willingness to engage in that aspect of community participation. As well, participants commented on the inadequacy of current health promotion materials in Canada in addressing their specific health promotion needs, saying that they are forced to look elsewhere to get information on physical activity. It is important to note that many of the barriers cited by the participants in this study are not unique to those with physical disabilities, but are universal

barriers to physical activity. These barriers have been studied in both populations, and the effects on those with physical disabilities is different in quality and quantity (Rimmer, et al., 2004).

Due to Sharon's negative experience at a fitness facility for people with disabilities discussed above, she now participates in less physical activity than she did previously. Although Nicole is physically active at the rehabilitation gym where she is a member, she is limited by the few hours of operation each week that the facility is open, and she finds it difficult to incorporate physical activity into her lifestyle outside of this facility due to accessibility barriers. Similarly, Judy finds it most comfortable to be active in the context of physical therapy, finding other situations intimidating or uncomfortable. Commenting on the Canadian health promotion materials currently available, she said that for people with disabilities, "ultimately their physios will be the ones to give them the best suggestions." Judy does not feel that other fitness professionals have the knowledge and motivation to assist people with disabilities in their physical activity participation, and that current health promotion resources do not adequately explain the physical activity requirements for people with various disabilities. In response to the question of where she would look for information on physical activity, Melanie responded that she prefers resources that make specific reference to her disability, as other resources do not provide specific information that she can use. Commenting on the Canadian Physical Activity Guidelines, Melanie pointed out that the document is far "too general" to be of use for her, and she does not consider it to be an adequate resource.

Another important discourse that I found in the discussion of physical activity is the discourse on treatment. In my interviews, rehabilitation was considered the most effective treatment for disability. When disability is medicalized, its 'treatment' is left in the hands of medical and health professionals, whose job it is to rehabilitate those with disabilities to get

better or achieve whatever functional independence is possible (Ustun, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). Judy described how most of her physical activity participation is through physical therapy sessions, and other exercises that are prescribed by her physical therapist. She said the doctors are “not at all” an effective resource for information on physical activity, but that her physical therapist provides all the information she needs to keep active. She said that for people with physical disabilities, she thinks that “ultimately their physios will be the ones to give them the best suggestions.” While the specialized knowledge of physical therapists was considered crucial in establishing physical activity or exercise programs, it also highlights repercussions if an individual does not have regular access to physical therapy sessions and their GP is not well-informed on PA guidelines (Rimmer, et al., 2004). Additionally, the overreliance on very specialized health professionals may prevent people with disabilities from achieving independence, in the sense that they have the autonomy to manage their own activities and participation. Even with the PA guidelines for SCI in hand, Sharon commented that she “would like to see this used in cooperation with a therapist who can assist, assess and assist with the day-to-day activities.”

In my interviews with Judy, Melanie, Sharon and Nicole, I found a few crucially relevant theoretical themes that are intimately linked with the dominant societal discourses relating to disability in Canadian society. The definition of disability is a contested topic in the literature on physical activity and critical disability studies, yet I found that the participants in this study related to physical disability in medicalized terms and attitudes, as indicated in Table 3 – Definitions of Disability, in keeping with the discourse of the biomedical model of disability that comes out strongly in health research. A consequence of the biomedical model of disability is the exclusion of those with disabilities from various spheres of daily life, and this was consistent

with the perceptions of people with disabilities in Canadian society that the participants described. Lastly, the medical model of disability lends itself to the solution of rehabilitation, as opposed to integration and solving basic societal inequalities, such as access and citizenship issues, wherein the participants felt strongly that the best resource available to them in terms of keeping healthy and active is health professionals, such as physical therapists, as opposed to PA guidelines that promote independent participation and adherence.

Findings - Practical Themes

Study participants were asked to comment on the perceived relevance and usefulness of a number of PA guidelines that are currently available. The documents provided to them were the Canadian Physical Activity Guidelines (CSEP, 2011), the American Physical Activity Guidelines Chapter Seven: Considerations for Some Adults, which includes considerations for adults with various disabilities (U.S. Department of Health and Human Services, 2008), and the newly released Physical Activity Guidelines for Spinal Cord Injury, developed by SCI Action Canada (2011). The three documents reviewed by the participants are widely available on their respective websites, and are evidence-based guidelines that have undergone rigorous peer-review processes.

The overall impression of the Canadian Physical Activity Guidelines handout was that it was a good start in terms of teaching people about physical activity, but not necessarily an effective resource for people with physical disabilities. The reasons offered included a lack of images of people with physical disabilities to which the participants could relate, few appropriate/applicable examples of physical activity that participants could perform, and the overall brevity of the document, which they felt was not sufficient to achieve its goal of

promoting physical activity in an effective way. Some of the discourses prevalent in the Critical Disability Studies (CDS) literature that were touched upon by participants in their discussion of the Canadian Physical Activity Guidelines included exclusion, ableism, and the notion that physical disability is only a set of functional, physical limitations, rather than something that may inhibit physical activity participation for reasons of access, attitudinal and other barriers.

When asked to comment on the chapter of the American Physical Activity Guide that deals with adults with disabilities, participants felt that while the chapter was a step in the right direction, it was still an insufficient resource for their needs. The chapter includes only text and no images at all. Judy commented that it is “very wordy and people don’t like reading that much,” a sentiment echoed by the other participants. Nicole was disappointed that there were no images in the chapter, making it difficult for her to relate. Additionally, all the participants commented that while it is a positive step to include people with disabilities, there were still very few practical examples given of how to incorporate the physical activity recommendations into everyday life.

Lastly, study participants were asked to comment on the new Physical Activity Guidelines for Spinal Cord Injury released by SCI Action Canada (2011). While not all participants have spinal cord injuries, the guidelines are applicable to adults who have issues with mobility requiring them to use a wheelchair or scooter, as do all of the study participants. Participants were pleased with the inclusive language of the document, and the specific recommendations it offered that were directly applicable to them. Sharon remarked on how easy the guidelines were to understand and use, and that the end-user would not have to spend time interpreting the document and trying to figure out exactly what it means before taking steps to incorporate the recommendations.

The physical activity guidelines for spinal cord injury offer substantially different recommendations for weekly physical activity than the Canadian and American guidelines, including the American guidelines for people with disabilities. The evidence for these guidelines is based on a systematic review of all research done in the past several decades on the exercise response in spinal cord injured people, which has been observed to be significantly different than that of a person who has not sustained a spinal cord injury (Martin Ginis, et al., 2007; Jacobs & Nash, 2004; Myslinski, 2005). Consequently, the process of establishing these guidelines, though it followed the same rigorous and transparent protocol as used to establish the Canadian physical activity guidelines, was entirely separate with regard to the evidence used, and used only high quality studies of the spinal cord injured population (Martin Ginis, et al., 2011).

The second aspect of developing the physical activity guidelines for spinal cord injury that bears relevance to this discussion is the use of focus groups and qualitative research methods to formulate effective strategies for developing and disseminating the guidelines (Latimer, Martin Ginis, Perrier, 2011). The physiological differences to exercise response were an important factor in the decision to create guidelines specifically for this population; however, the various barriers faced by people with spinal cord injuries were also taken into account, as well as incorporating the most effective possible strategies for delivering the message to this population. By consulting with people who have spinal cord injuries in the development of this resource, while maintaining a rigorous and transparent commitment to the concept of evidence-based guidelines, the research team involved with this project has created a usable resource, which will hopefully be proven effective with this population.

The actual physical activity recommendation of 20 minutes of moderate to vigorous aerobic activity twice a week and two bouts of resistance training per week using each major

muscle group (SCI Action Canada, 2011) are quite different from the recommendations presented in the other guidelines. The most recent edition of the Canadian PA guidelines recommend at least 150 minutes a week of moderate intensity aerobic activity, as well as resistance activities performed two days per week (CSEP, 2011). The American PA guidelines recommends that adults with disabilities participate in at least 150 minutes per week of moderate intensity aerobic activity, or 75 minutes per week of vigorous intensity aerobic activity, as well as muscle-strengthening exercises two or more days per week that involve each of the major muscle groups. Instead of elaborating on the specifics of how to do those kinds of activities, the guide went on to say that adults with disabilities should consult with their health-care providers regarding the appropriate activities for them (U.S. Department of Health and Human Services, 2008).

The comments provided by study participants regarding this resource are uniformly positive, with the one caveat that they would like to see more detail and examples provided (a project that is already underway by SCI Action Canada). Nicole said that she appreciated the detailed “how-to” section that provided information on exactly how to exercise, though she would appreciate diagrams and more detailed examples. Melanie found the specific exercise prescription to be very helpful, as other PA guidelines provide no information on the different amount of PA required to achieve health benefits if you have any type of disability. Melanie sees the SCI PA guidelines as a document that someone with a spinal cord injury could pick up and actually use to become more active, as the message is so well tailored to that population. Similarly, Judy commented that the SCI PA guidelines give more concrete ideas of what people who use wheelchairs can actually do, other than just wheeling. However, Judy also feels that physical therapists remain the most important resource for information on physical activity and

exercise. The dissemination of these guidelines to physical therapists and other health care practitioners remains an important goal for the SCI Action Canada team (Martin Ginis, et al., 2011). Sharon appreciated that the SCI PA guidelines were specific and usable, saying, “it’s broken down in a way that you can get the information quickly and move on to the next step.”

After presenting to the study participants a few of the current health promotion resources to them for their review, they were asked to elaborate on what they would like to see included in future physical activity guides for those with physical disabilities, especially in light of the issues they pointed out concerning the current resources available. The opinions expressed by the interviewees convey the fragmentation of the current set of health promotion resources available, and potential positive outcomes of a cohesive health promotion strategy that takes into account physical activity, nutrition, and a more holistic, whole body approach to health. For example, Melanie expressed her desire for a more holistic approach, in a document that would consist of different sections dealing with various aspects of health and fitness, including recommendations and strategies to work on “the mind, body and spirit.” Sharon, Judy and Nicole all agreed with this idea, Sharon especially highlighting the need to address the unique psychological barriers to physical activity that many people with disabilities face.

The finding that study participants desire a more holistic health promotion document to meet their needs does not necessarily point to a specific barrier in accessing physical activity, but that the current knowledge and promotion of evidence-based guidelines for physical activity, nutrition, social determinants of health (i.e., social support) among this population is insufficient. In general, the study participants expressed the view that not enough is being done in Canadian society to meet the needs of those with physical disabilities.

As stated earlier, study participants feel that their role in Canadian society is marginal, or diminished, by others because of their disability. The question remains, however, of how to address this issue, and who bears the responsibility for addressing this issue both in the short and long term. Study participants were asked to give their opinions on this issue, and the results illuminate the lack of clear direction and onus of responsibility with respect to remedying the issues people with physical disabilities face in Canadian society.

Within the group of study participants, Sharon has the most advocacy experience for people with disabilities in Canada. When questioned as to who bears the responsibility for improving the quality of life for people with disabilities, she expressed the need for all relevant players, different levels of government, academics, charities, activists and end-users, to form an overall body that is committed to addressing the needs of people with disabilities, and lobbying for change. At the same time, Melanie stated her recognition that the funds to get such a group off the ground are certainly limited, and the specific focus on health promotion may get drowned out by some of the other issues that people may see as more directly impacting the lives of people with disabilities. Compounding this problem are the numerous advocacy groups in Canada that each advocate for different aspects of equality for people with disabilities. The Council of Canadians with Disabilities focuses on large-scale human rights issues, for example, while the Disabled Women's Network (DAWN) focuses more specifically on issues relating to women with disabilities in Canada. In addition, many specific types of disabilities each have their own advocacy organizations, such as the Canadian Paraplegics Association, the Canadian National Institute for the Blind and many others. Consequently, there is no cohesive disability movement in Canada that can act as a voice for all people with disabilities to advocate on the numerous issues that have yet to be addressed regarding equality and inclusion.

While Melanie recognizes the importance of a focused group effort to improve the quality of life for people with disabilities, she feels that end-users with disabilities also need to lobby on their own behalf to ensure their voice is heard. Melanie described situations she has been involved in where she felt that local government officials were purposely impeding efforts by the community to improve accessibility to public spaces due to by-laws and zoning restrictions that did not take into account the needs of those with disabilities. She feels that if enough people come forward to advocate on their own behalf, and on behalf of those with disabilities, the government at various levels will have to pay attention to growing pockets of discontent.

The range of answers to the question of who bears responsibility for addressing issues faced by the people with disabilities in Canada reflects the plethora of opinions often expressed in the disability rights movement, and the unclear expectations of where improvements can be made (Shakespeare, 2008). Throughout its relatively short history, this movement has suffered from a lack of clear direction and leadership, a problem compounded by a lack of consensus among scholars and activists about the most effective approach to advocacy and lobbying, and by disagreement about the very definition of the term disability (Shakespeare). The ensuing problematic discourse in this area is one that Oliver & Sappey term 'learned helplessness' on the part of the disabled community, where, especially in the realm of health promotion, there is a feeling that nothing can be done, and one simply has to make the best of a bad situation (Oliver & Sappey, 1998).

On a practical level, study participants identified a number of areas in which they hope to see improvements in the provision of health promotion resources for people with physical disabilities, including PA guidelines and other resources that may assist them in incorporating

physical activity into their lifestyle. These areas include better awareness and articulation of the specific barriers they face in accessing and participating in physical activity, guidelines that are more specific in regarding exercise prescription, increased availability of facilities that cater to their needs, more informed staff to assist them at those facilities that are available, and better overall awareness of their physical activity needs among health care practitioners. It is clear from their statements that there is dissatisfaction with current health promotion efforts, especially in light of the finding that three out of four interviewees had not previously accessed any of the physical activity guidelines presented to them in the interview. More effective cooperation and strategic partnerships between researchers, end-users and government policy makers is crucial to create lasting change.

Discussion

The analysis of the participants' responses revealed a number of prominent discourses, as well as the pervasive role of discourse, or common sense information, in shaping their relationship and access to physical activity. In the particular, the discursive concepts of rehabilitation and the negative perceptions of people with disabilities that they perceive play strong roles in how they access physical activity, and how they advocate for themselves, or choose not to. Participants, especially Sharon and Melanie, expressed a feeling of marginalization and exclusion, based on their disability, while Judy, Sharon and Nicole are only able to find appropriate outlets for physical activity through rehabilitation programming. Despite advances made in the disability advocacy movement over the past generation (Shakespeare, 2008), discourses such as these continue to play a role in reproducing the dominance of able-bodied participants over their disabled counterparts. Although participants expressed the hope for

more effective lobbying groups and organizations to promote inclusive policies, there is no clear consensus on how that can be done effectively to promote change that will help them more easily incorporate physical activity into their lifestyles in ways that promote both inclusion and independence.

The discourse of rehabilitation as the appropriate approach to dealing with disability (Pledger, 2003) was especially clear in the responses of Sharon and Judy. Both of these women rely on physical therapists for the majority of their physical activity participation, and physical therapists are also the people they trust most to advise on issues of physical activity participation. While it is important that physical therapists, and other health care providers, continue to function in this capacity, not all people with physical disabilities have access to physical therapy treatment, due to financial constraints, nor is it necessarily the best or only approach for people with physical disabilities who may not agree with the notion that they must constantly be rehabilitated (Westbrook, Legge, & Pennay, 1993). While rehabilitation plays an important role in the acute phase of an acquired disability, it is important that the end goal is to help the individual develop their own resources, knowledge, and aptitudes to deal with daily life and maintaining health (Westbrook, Legge & Pennay).

Closely tied-in with the discursive concept of rehabilitation is the medical model of disability. The responses of study participants to the question of how to define disability were all firmly rooted in the medical definition of disability. The barriers to physical activity participation most commonly noted by study participants were related to physical barriers in the environment and attitudes of fitness professionals. Transportation issues and lack of overall knowledge on guidelines and opportunities to participate in physical activity, all of which are modifiable through effective lobbying for social change, were less frequently discussed. There is

incongruence between the reality facing people with physical disabilities, where a lack of social change results in a number of barriers to their full societal participation, and how they perceive that disability as a concept impacts their lives.

Participants were asked to describe their perception of disability in opposition to the concept of ability. Their responses focused on impairment and the functional limitations associated with disability. While this finding may point to the slow trickle-down effect of the disability movement in effecting the attitudes of those living with physical disabilities today, it remains a relevant point that those individuals I interviewed on the subject of physical activity see the biomedical characteristics of disability as more relevant to their day-to-day lives than the social inequalities disability scholars point out in the literature. Especially when dealing with issues related to physical activity and PA guidelines, the medical model of disability has prevailed in the literature thus far (Martin Ginis & Hicks, 2007), even while more socially oriented studies of disability have wholly embraced the different facets of the social model of disability (Thomas, 2007). When questioned about the possible relevance of the social model of disability, which defines disability as an issue of societal inequalities, each of the study participants agreed that it also provides a valuable framework to understanding the larger issue of disability in society, but it is not necessarily what they feel effects them on a day-to-day basis.

The finding that the biomedical model of disability still plays a role in the perceptions of those I interviewed points to the relevance of the dominant societal discourse of disability as residing within the effected individuals. The consequences of the dominance of this discourse have been documented throughout the critical disability literature, and include a lack of motivation to change the status quo by and on behalf of those with disabilities, an inappropriate focus in the research on the personal tragedy aspects of disability, rather than on solving the

problems of social organization that contribute to the negative experience of disability (Barnes & Mercer, 1997), and the overall medicalization of disability, where treatment and rehabilitation are mandated by healthcare professionals, and little autonomy is taken up by those with disabilities (Ustun, et al., 2003).

While it is difficult to posit that the medical model of disability is in and of itself a barrier to societal participation, or to physical activity participation, a connection can be made between the medical definition of disability encountered in the interviews and the lack of clear direction for future change expressed by the study participants. When disability is viewed as a medical pathology, rather than a social issue, it can be difficult to envision how social change can address the issues important to promote inclusion and participation. It is only when disability itself is recognized as at least partly an issue of inequitable social organization that effective practical solutions can be implemented.

Limitations

This study was conducted using a sample of four participants, all of whom have physical disabilities that limit their mobility, all of whom were recruited from one physical therapy clinic. There is a large range of physical disabilities unrepresented in this study, and the results may be different with that perspective included. The researcher is an individual with a disability of mobility, and that perspective frames her response and perception of what was said in the interviews.

Conclusion

Further qualitative studies exploring the perspectives of people with physical disabilities in the realm of physical activity and health promotion are important so that future efforts of inclusion can take into account their unique perspectives. The work of the SCI Action Canada team (2011) has taken this approach into account, and other PA researchers should carefully consider the inclusion of this perspective in their future work.

Van Dijk (2009) explained that in order to combat problematic discourse, new counter-discursive notions must come into wide use. Research into how to disseminate a more socially oriented theory of disability to the general population will be an important step towards demystifying the concept of disability, among both disabled and able-bodied people. Effective social change hinges on the widespread adoption of a socially rooted model of disability, making the issue of how to accomplish an important research priority.

The Canadian federal government invested significant funds and research into the creation of the Canadian Physical Activity Guidelines since the early 1990's (Sharratt & Hearst, 2007). These guidelines provide an important resource for Canadians who wish to incorporate more physical activity into their lifestyle, and it is important to note that attempts are made throughout the guidelines to be inclusive of those with physical disabilities. An example of this inclusion is the use of images of individuals in wheelchairs and using mobility aids such as canes throughout the handbooks. However, the guidelines are based on evidence gathered from studies on the general population, not people with disabilities, and no separate recommendations are presented in these guidelines for people with different types of disabilities. It is not clear whether individuals with physical disabilities consider the Canadian physical activity guidelines to be an effective and relevant resource in their lives. While the use of terms, such as "wheel," and the use of images of people using wheelchairs are an important first step towards inclusion in health

promotion literature, the sample interviewed in this study found these guidelines to be an insufficient resource, pointing out the need for more specific guidelines that offer concrete suggestions that they can incorporate into their lives.

Currently the only PA guideline available to the disabled community is for adults who have sustained a spinal cord injury (SCI Action Canada, 2011). These guidelines are an important step forward, but there remains room for the development of additional guidelines that address other disabilities, requiring a significant investment of research funds into studying these populations and formulating an evidence base to support those guidelines.

An additional consideration in remedying this situation is the adoption of a more socially oriented model of disability among researchers and policy makers that accounts for the unique social barriers to physical activity faced by people with physical disabilities. Martin Ginis and Hicks (2007) pointed out that the research dealing with physical activity for people with physical disabilities has approached the issue of disability from the medical perspective. She calls upon the research community to be receptive to integrating the social model of disability. The willingness of researchers to take this recommendation seriously will be a crucial determinant of the effectiveness of future research programs that study physical activity for people with physical disabilities.

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Chapter III

A Discourse Analysis of Canadian Health Promotion Resources: The Stakeholders'

Perspective

Abstract

Twelve percent of Canadians have a physical disability affecting their mobility, in comparison with the overall fifteen percent disability rate, and the aging population assures that this percentage will increase. Although the Canadian government has taken steps to promote inclusion of this population segment in all aspects of Canadian society, an area in which they are routinely excluded is physical activity participation. My proposed research seeks to explore the discourses prominent in health promotion for people with physical disabilities that hinder their ability to fully participate in this important healthy behaviour. Literature indicates that people with physical disabilities engage in far less physical activity than the non-disabled population. One of the main forms of health promotion messaging Canadians receive are the Canadian Physical Activity Guidelines, developed through the Canadian Society for Exercise Physiology. Additionally, ParticipACTION acts as the main promotional vehicle for physical activity in Canada. Until recently, there were no published evidence-based PA guidelines for any disability. Studies have also looked into the construction of disability, and the different frameworks that have been used in its study. I discovered that although there has been a lot of research conducted on exercise response among those with physical disabilities, fewer studies have explored the biases inherent in the research process itself, as well as the downstream issues of resource development and service delivery. Even fewer studies have been conducted using qualitative methods. This paper will explore the gaps in the current health promotion program in Canada, and their impact on people with physical disabilities. Results from semi-structured interviews

with stakeholders in the fields of health research, promotion and advocacy for people with disabilities will be presented and analyzed with a goal to understand where the issues lie, how they can be addressed, and who bears the responsibility for furthering the promotion of physical activity among people with physical disabilities.

Key Words: Physical Disability, Health Promotion, Stakeholders, Medical Model, Social Model, Discourse, Critical Disability Studies

Introduction

The government of Canada has long been involved in the promotion of physical activity as a national priority. Since the 1990's, physical activity guidelines were established and disseminated through community and schoolboard programs. From its inception, ParticipACTION has played a prominent role in the national effort to improve the health of Canadians through physical activity participation, and they are considered to be "the national voice of physical activity and sport participation in Canada" (ParticipACTION, 2011). An additional avenue through which the promotion of physical activity occurs is through the various research funding bodies that allocate research grants. These researchers provide evidence-based research or critical reflections to help shape good practices for ParticipACTION programming and communication.

Starting in the early 2000's and on an ongoing basis, the Canadian federal government established a mandate of promoting increased equality and full citizenship for Canadians with disabilities (Human Resources and Skills Development Canada, 2010). The seeds of such policy priorities were planted in the political activism of the disability movement in the late 1970's through the 1990's (Shakespeare, 2008). The stated goals of this initiative include less income disparity and discrimination in hiring practices, more community participation, improved access to aids, improved access to health care and the overall removal of barriers that inhibit the full participation of people with disabilities in Canada. Improved access to health care includes the accessibility of health resources and community participation that foster healthy living, but it remains unclear, as of the most recent Federal Disability Report for 2010, what initiatives have been undertaken to improve the health of Canadians with disabilities.

At this time, people with disabilities report low levels of physical activity and poor levels of overall health compared to those who do not have disabilities (Martin Ginis & Hicks, 2007). A number of scholarly works have shed light on some of the barriers people with disabilities face in accessing physical activity and other health resources (Rimmer, Rubin, & Braddock, 2006; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Scelza, Kalpakjian, Zemper, & Tate, 2005); however, these papers define physical disability in medical terms, and focus on the barriers that are internal to the individuals, rather than those that exist on a societal level. An example of this definition is found in Scelza, et al. (2005) where psychological factors are given prominence as a barrier physical activity participation, but other factors, such as inaccessible equipment are of lesser consequence. In this paper, an attempt will be made to focus on the barriers to physical activity that are related to policy and societal exclusion, using the social model of disability, first defined by Shakespeare (2008):

“Rather than inhering solely in the individual, or their medical problems of body or mind, disability is reconceived as a political issue, in the same way as other issues such as class, race, gender and sexuality. Attention shifts from care, cure and rehabilitation to barrier removal, anti-discrimination statutes and independent living. Rather than being shamed or invisible, disabled people can develop an identity politics approach, in which they can express solidarity, pride and resistance” (p. 236)

A focus on the social model of disability is the political project of advocates for equal rights and full citizenship for those with disabilities (Devlin & Pothier, 2005); this will be a crucial theme throughout this paper.

The health promotion policies and programs designed for people with disabilities are shaped by a number of different organizations, made up of stakeholders and advocates for people

with disabilities. In this study, stakeholders from key health promotion and advocacy organizations were interviewed to get a picture of the current situation of health promotion materials available to people with disabilities, as well as explore the ways in which the delivery of services and the development of materials can be improved in the future. The stakeholders are individuals who are involved in developing these materials, such as PA guidelines, or involved in the delivery of physical activity services and opportunities for people with disabilities.

In this paper the following questions will be addressed:

1. What are the needs of people with disabilities with respect to health promotion, and where do those needs fit into the federal government's attempt to promote physical activity in the general population and equality for people with disabilities in Canada?
Important references will be the current health promotion resources available to the general population and those with disabilities.
2. Are those needs being adequately addressed through the programs and initiatives referenced in the Federal Disability Reports over the last few years?
3. From the point of view of those involved in developing health promotion materials, what are the strategies needed to address physical inactivity among those with disabilities in Canada?
4. From the point of view of those actively promoting physical activity for people with disabilities in Canada, what strategies are needed to improve their delivery of services and health promotion materials?
5. What are the problematic discourses in health research, health promotion, and government spending that perpetuate the inequitable situation that currently exists for people with disabilities in Canada, and how can these discourses be addressed?

In addressing these questions, it will be possible to identify the weaknesses and gaps in the current health promotion program in Canada, as well as strategies in both policy and research initiatives that can be used to promote improved health for people with disabilities in Canada, and ultimately contribute to a better quality of life.

Method

Qualitative research methods are often used in critical disability studies to capture detailed accounts of the experiences of people with disabilities (Hartley & Muhit, 2003). In this study, however qualitative methods are used to obtain in-depth knowledge of current issues in health promotion for people with disabilities in Canada, as well as the strategies for addressing those issues. This topic is not currently well researched, with even fewer studies using qualitative methods, so a qualitative exploration is warranted. An additional advantage of using qualitative methods in this study is that participants were free, and, indeed, encouraged, to interject with their own experiences and draw on their knowledge of the subject, rather than be constricted by a more precise measuring tool that would not allow for such elaboration.

In addition to interviews with study participants, an environmental scan of current health promotion materials available to Canadians was undertaken for the purpose of providing context regarding their applicability and relevance to people with disabilities, and to identify problematic discourses that are present in these materials. The purpose of using qualitative methods to carry out this analysis is that it incorporates issues of difference and conflict into the analysis, rather than simple frequency counts (Fairclough, 2003).

Participants

In this study, a small group of participants (n=4) agreed to be interviewed on their knowledge of physical activity initiatives and resources for people with disabilities in Canada. Participants were recruited based on their involvement with research projects on health resources for people with disabilities, or their direct involvement in promoting healthy behaviours among people with disabilities.

Few research teams in Canada are dedicated to the development and dissemination of health promotion materials for people with disabilities. As well, there are a small number of organizations whose mandate is to promote healthy behaviours to this segment of the population. The criteria for participation in this study was an association with such a research group or organization. As well, those interviewed had significant knowledge on the development of health promotion materials for the general population, and were in a position to comment on how effective those materials are at reaching and impacting those with disabilities.

Helen works on a research team dedicated to the development of health promotion materials for people with spinal cord injuries. The main focus of her research is in the exploration of health-related behaviour change among people with different disabilities.

Arlene also works on a research team dedicated to the development of health promotion materials for people with disabilities. The focus of her research and contribution to this project is with respect to message framing, and the special considerations to implement when framing messages for people with various disabilities.

Thomas works for an organization dedicated to the promotion of physical activity among Canadians with disabilities. His role is in the development of community partners in order to create more opportunities for people with disabilities to participate in physical activity.

Claire works for an organization dedicated to advocacy for people with disabilities across all sectors of Canadian society, including health, education, human rights and social policy. Her role is to prioritize key projects to undertake for and on behalf of people with disabilities in Canada.

Data Collection

The interview guide was developed by the principal investigator, and was specifically tailored for this group of well-informed stakeholders. Slightly different versions of the interview guide were used depending on the affiliation of the participant, whether they were involved in health research or health promotion for people with disabilities. Both practical concerns regarding physical activity participation and the, and theoretical concerns regarding the role and perceptions of people with disabilities in Canada were addressed in the interview guide. Ethics approval was obtained from the Research Ethics Board at the University of Ottawa.

Health promotion materials that were analyzed include the most recent version Canadian Physical Activity Guidelines (CSEP, 2011), the ParticipACTION website and its associated promotional materials (ParticipACTION, 2011), the American Physical Activity Guidelines (U.S. Department of Health and Human Services, 2008), and the SCI Action Canada Physical Activity Guidelines for Adults with Spinal Cord Injury (SCI Action Canada, 2011).

Practical concerns include the applicability of current health promotion resources for those with disabilities, the roles of academic researchers and advocacy organizations in promoting physical activity, and the strategies participants felt would be successful in addressing any inequitable situations that might exist. Theoretical concerns include the benefits and drawbacks of both the medical and social models of disability in health research and policy development, the concept of citizenship as it applies (or does not apply) to people with

disabilities in Canada, and a discussion of the potential hierarchical division in Canadian society along the lines of ability and disability, and its consequences.

Each participant was interviewed one time and each interview lasted approximately 40 minutes. All interviews were digitally recorded and manually transcribed by the principal investigator. Interview transcriptions were returned to the participants for their review and revisions. Revised versions of the interview transcriptions were used for the data analysis phase of the study.

Data Analysis

Interview transcripts and health promotion documents were analyzed using Norman Fairclough's (2003) protocol for analyzing texts with regard to discourse. In this form of critical discourse analysis (CDA), special attention is given to the role of differences, dominance and resistance in the linguistic aspects of what was said by those interviewed and expressed in the texts, and the discourses referenced by each participant and document (Wodak & Meyer, 2009). Discourse, a concept with various meanings depending on the context, in this study refers to the way in which features of the social world are understood along the lines of a particular social perspective (Fairclough, 2009). Discourses are referenced when participants express a view that is in line with taken-for-granted ideas regarding disability and health promotion, as expressed in the academic literature on those respective topics.

The principle investigator manually coded interview transcripts and health promotion documents in order to generate a list of categories that featured prominently in the analyzed materials. Lists of categories were then referenced against each other to see which views were commonly held among study participants, as well as what discourses were common to the health

promotion materials, and where opinions differed regarding both what the issues are, and where the solutions are to be found. A list of categories was created for each participant, and was compiled into one list, shown in the table below, that takes into account the themes commonly cited among all participants.

Table 1

Stakeholder Categories/Themes

Category/Theme	Example from Interview
Funding	“I think particularly with SSHRC, SSHRC is very much lacking. Any mention of the word physical activity and your proposal gets thrown out.” “Canada was leading the pack in terms of developing new physical activity guidelines, however, resource allocation ceased and then Canada fell behind the process.”
Strategies to promote PA to people with disabilities	“It’s not like you can have guidelines that are going to meet the needs of all the divisions of disabilities.” “I think all research has to be participatory.”
Unmet needs for health promotion among people with disabilities	“I don’t think that it (Canadian PA guidelines) meets the needs. I think that the evidence that’s out there to develop those guidelines don’t include studies with disabilities, so yeah, no, they do not meet their needs.”
Definition of disability	“An ‘impairment’ hindering normal functioning and normal being defined by society.”
Citizenship	“No, I don’t think so because ... all the barriers haven’t been removed yet, haven’t been addressed.”
Barriers to physical activity participation	“Universal design is not always fully understood by people who are developing public spaces.” “Cost, transportation, lack of knowledge on the part of activity leaders, lack of knowledge on the part of people with disabilities with regard to what is available out there.”

Findings

The findings of this study are organized according to the above-stated questions that guided the interview and data analysis processes. First, where the needs of people with disabilities fit into the current collection of health promotion materials made available by both

the government and health promotion organizations. Second, are their health promotion needs being adequately addressed by the programs and initiatives currently in existence? Third, what are the unique strategies needed to promote healthy behaviours among people with disabilities? Fourth, how can the dissemination of materials and the delivery of services be improved? Fifth, and lastly, what are the problematic discourses in health research, health promotion and government spending that add to this problem?

(1) Health Promotion Materials in Canada

Helen and Arlene referenced the Canadian Physical Activity Guidelines as an important resource for non-disabled Canadians who are looking for information on physical activity.

Thomas, however, pointed out that special health promotion strategies are required to address the needs of those with disabilities, and that the Canadian Physical Activity Guidelines are an inadequate resource for this purpose.

Analysis of the Canadian Physical Activity Guidelines showed that little reference is made to people with disabilities and how they should incorporate physical activity into their lives. Images are predominantly of able-bodied people, and those examples that are given that are inclusive of people with disabilities only apply to a small segment of the disabled population. For example, there is an image of a man using a wheelchair alongside a woman riding a bicycle. There is an attempt to minimize the differences between those who have disabilities and those who do not by making the suggestion that people “walk or wheel” to school, work and other community activities (CSEP, 2011). In doing so, the unique challenges of people who use mobility aids, such as wheelchairs and walkers, are largely ignored, as they are lumped in with the general population. Similarly, many of the promotional advertisements for physical activity

found on the ParticipACTION website display the same disregard for difference, as walking is equated with wheeling in a number of places, such as “Take a walk or wheel after supper and make it an adventure” (ParticipACTION, 2011).

While the Canadian Physical Activity Guidelines are an important resource for Canadians, Helen was careful to point out that they do not meet the needs of people with various types of physical disabilities, both in terms of the kind of message they give, and the practical examples they offer with respect to incorporating physical activity into daily life. Helen emphasized the need for resources that are specifically tailored to the needs of people with disabilities. She cautioned that one cannot group all people with disabilities together into one guide, as is the case in chapter seven of the American Physical Activity Guide, entitled “Considerations for Some Adults” (U.S. Department of Health and Human Services, 2008). There has been some significant progress made, particularly SCI Action Canada developing the first physical activity guidelines for adults with spinal cord injury (SCI Action Canada, 2011). The next phase of this project is to disseminate these evidence-based guidelines through health promotion materials targeted to all segments of the population. The table below depicts the PA resources currently available to Canadians and the various features they offer to the general population and those with disabilities.

Table 2

Current Canadian Physical Activity Resources

PA Resource	Includes language referring to individuals with a physical disability	Includes images referring to individuals with a physical disability	Specific exercise guidelines for disability	Resources and links provided	Addresses specific barriers to participation
SCI Action Canada	√	√	√	√	V
Canadian PA Guidelines	√	√	X	X	X
ParticipACTION website	√	√	X	X	X

The responses offered by Helen and Arlene offer further clues into why people with disabilities are less physically active than the general population. The work of Rimmer, et al. (2004) and others has previously focused on environmental (i.e., buildings, programs, etc.) and psychological barriers to physical activity for those with disabilities, but here we find that the lack of available resources and guidelines is another factor in this issue. It is noteworthy, however, that this barrier to physical activity participation can be remedied through research and knowledge translation on the part of academics and advocacy groups.

Claire's perspective on the current resources available to people with physical disabilities regarding physical activity was that the resources are not all that available to them in the first place. She pointed out important issues, such as the lack of accessibility of websites and printed materials for this population, and the importance of creating two streams of resources so that their needs can be adequately addressed. Thomas pointed out that not only are more resources needed to address this issue, but that more organizations to promote physical activity for people with physical disabilities are needed.

(2) Current Initiatives Geared Towards People with Disabilities

Relevant programs and initiatives by Canadian federal government have been implemented over the last several years to promote equality and inclusion for people with disabilities. There have been significant funds allocated towards improving accessibility and inclusion in many spheres of life, including health, education, retirement planning, and housing (Human Resources and Skills Development Canada, 2010). These programs include the Athlete Assistance Program for athletes with disabilities, CIHR research grants allocated for research on disability, Housing for Persons with Disabilities, and Vocational Services among many others. The annual Federal Disability Report draws attention to the areas in which there have been improvements in accessibility and inclusion for those with disabilities, and where programs continue to fall short of this goal.

All study participants expressed the opinion that current initiatives, such as the ones listed above, are not an effective means to promoting healthy behaviours among people with disabilities in Canada. Although the Federal Disability Report highlights where funding has increased for several programs, some related to sports and athletics (Human Resources and Skills Development Canada, 2010), those interviewed expressed their dismay at the reduction in funding they have noticed to health promotion initiatives, especially from the Social Sciences and Humanities Research Council of Canada (SSHRC), where the mention of physical activity in a grant proposal results in its being rejected.

Many of the program initiatives currently funded by the Canadian federal government support Paralympic and other high level athletes with disabilities, but relatively little funding is

allocated towards community-based efforts to promote healthy behaviours in this population.

Thomas, who works to develop programs in the community for people with disabilities, expressed his frustration, firstly with the inadequate funding his organization receives to carry out its work in the community, and secondly that funding amounts differ from year to year, making it difficult to plan programs over the long term. He spoke about the Public Health Agency of Canada, “where most of our support *used to* come from, but there is very little support there now to promote physical activity. I would say that the federal government’s not doing a very good job of promoting physical activity and supporting organizations that do that.”

Claire articulated her frustration with the pace at which progress is taking place in making Canada accessible for all segments of the population. While she acknowledged the steps being taken to remedy inaccessible websites, buildings and public spaces, she feels as though each specific issue is an uphill battle for recognition and legitimacy among people with disabilities. Issues like health promotion and PA guideline development will necessarily remain unaddressed while such basic societal issues of inclusion are yet to be addressed.

(3) Strategies to Address Physical Inactivity Among Those with Disabilities

From the findings above, it is clear that the current strategies for promoting healthy behaviours among the general Canadian population are not reaching much of the disabled population, or at least not as effectively. The question remains as to what are the specific strategies required to effect change in the physical activity patterns of this segment of the population. A limited amount of research has been conducted on this topic with respect to message framing in health promotion materials (Letts, Martin Ginis, Faulkner, Colquhoun, Levac, & Gorczynski, 2011; Latimer, Brawley, & Bassett, 2010), and many of the questions in

this area are yet to be well studied. Study participants offered their opinions both on specific strategies to promote physical activity, and the methods by which researchers should approach this question in order to devise effective solutions.

Helen articulated the need for a research process that is inclusive of those with disabilities and takes their viewpoints into account. She pointed out a couple of examples of participatory action research that she felt accomplished this goal, and she thinks that the results of studies like that are extremely valuable additions to the literature. One such study is Letts, et al. (2011) where focus groups were used to devise effective health messaging strategies for people with spinal cord injury. In this study, qualitative, participatory research was used, and the participants were able to state their thoughts and opinions, rather than just be the subject of tests and measuring tools. The importance of incorporating the detailed accounts of people with disabilities is well documented in the critical disability studies literature (Hartley & Muhi, 2003), but that does not always translate into inclusive research practices from those who are studying health promotion. Inclusive research practices mean that not only are people with disabilities asked for an opinion on matters relevant to them, but they are also active participants in the research process, including the process of formulating the questions under study.

The most clearly articulated idea among the study participants for a strategy to promote physical activity among people with disabilities was the development of specific resources that address the issues relevant to that population. This is a difficult task, as the specific exercise prescriptions are different for each type of disability to achieve health benefits, and the barriers faced by each group also differ greatly. For example, Becker and Stuifbergen (2004) found that people with multiple sclerosis and polio report interpersonal issues in the exercise setting as a major barrier to physical activity, while Vissers, et al. (2008) reported that people with spinal

cord injuries find that physical accessibility into physical activity facilities is the biggest barrier to their participation. Arlene highlighted the importance of resources with this level of detailed information, but remarked that at this point in time, there are barely resources out there for the general population of that level of sophistication. There are no supplementary materials that go along with the revised Canadian Physical Activity Guidelines at this time, only a one-page fact sheet. Arlene felt that the strategies for promoting health among those with disabilities are not really so different from the general population, but it is simply a matter of funding and time for such resources to be developed. At this point in time, there is a resource available tailored to meet the needs of adults with spinal cord injury, but no such guidelines have been developed for other types of disabilities. The guidelines available for adults with SCI were compiled based on the review of almost 100 scientific studies. The next phase of this project includes promotion and dissemination of these guidelines.

Thomas similarly expressed the idea that the actual delivery system for health promotion materials does not need to be reinvented in order to meet the needs of those with disabilities. The most important component of a health promotion program for this segment of the population is that the unique barriers to physical activity participation that exist among different types of disabilities be addressed. He commented that the use of inclusive language, such as including wheeling as a form of physical activity, is important, but falls far short of the mark in terms of addressing the needs of people with disabilities, and it does nothing to address the specific challenges and barriers that have been identified in the literature, such as lack of accessible opportunities (Vissers, et al., 2008), psychological barriers related to self-efficacy and motivation (Arbour-Nicitopoulos, Martin Ginis & Latimer, 2009), and difficulty communicating with fitness professionals (Becker & Stuifbergen, 2004). With respect to the physical accessibility of fitness

facilities, Claire made it clear that until real steps are taken to enforce universal accessibility standards, people with disabilities will be cut off from accessing those resources regardless of other accommodations put in place on their behalf.

Although preliminary results in the literature show the importance of tailoring messages for people with different types of disabilities in a different manner than the general population (Latimer, Brawley, & Bassett, 2010), there is also some indication from the small group of people represented here that the most important strategy for promoting physical activity among those with disabilities is to address the barriers they face. It is clear that further research is needed in this area to determine how best to promote physical activity in this population.

(4) Strategies to Improve the Delivery of Health Promotion Services

As discussed above, although there are real gaps in the development and dissemination of health promotion resources for people with disabilities in Canada, there is not necessarily a need to come up with completely new strategies and types of resources in order to meet the needs of this population. Similarly, regarding the delivery of health promotion services, there is not necessarily a need for a completely new system of providing these services; rather, there are a number of needs unique to this population that must be addressed, and in doing so it is largely appropriate to use the systems already in place throughout Canada.

An example of such a delivery system is ParticipACTION. As the national voice of physical activity promotion in Canada (ParticipACTION, 2011), they have the resources and funding to campaign for physical activity participation on a wide scale. While they do make certain attempts to use inclusive language and create a message for people of all abilities, there is

still a lack of specific material they create that is focused and relevant for people with disabilities. For example, ParticipACTION encourages people to get active by joining an “all-abilities” sports league, but does not provide any examples of such leagues, or information on where to find them. Similarly, people are encouraged to walk and wheel to work, home and school, but issues of motivation, self-efficacy and the physical barriers encountered in the environment by people with disabilities are glossed over, with no suggestions of resources and organizations to contact to help address these issues. Thomas expressed his certainty that the organizations focused on promoting physical activity and sport participation among people with disabilities are doing all they can within the current constraints. Where there is room for improvement is in the creation of strategic partnerships between ParticipACTION, for example, and health promotion organizations for people with disabilities. Such partnerships would allow the larger voices of physical activity in Canada to effectively reach people with disabilities, and help provide them with strategies for incorporating physical activity in their lifestyles.

The most often cited area of concern with respect to service delivery among study participants was lack of funding, or lack of clarity regarding future funding. Thomas pointed out that “direct support” in the form of government grants are very hard to come by for his organization, and this directly impacts his ability to do his job in reaching out to the community and making physical activity opportunities available. Thomas also emphasized the importance of the many partnerships his organization has established across Canada that assist in getting the message of physical activity out there for people with disabilities. Additionally, his organization has developed strategic links with school boards and private sector organizations. The topic of funding is especially pertinent to the organizations that rely on charitable donations as their source of funding. Claire explained the many roles her organization takes on in advocating for

people with disabilities in Canada, and the resources required to effectively lobby on their behalf. During times of economic trouble, charitable donations decrease, and the services provided by the organizations responsible for advocating for people with disabilities are cut. A more clear-cut commitment to ensure public and private funding will go a long way towards ensuring these organizations can continue their important work in the community and in the resource development process.

(5) Problematic Discourses Contributing to the Problem

While it is overly simplistic to report that the issues and gaps in the provision of health promotion materials for Canadians with disabilities can be attributed solely to discursive issues, there are a number of important discourses that play a key role in perpetuating the inequitable situation that currently prevents this population from fully participating in physical activity and other important healthy behaviours. The relevant discourses are situated in health research, health promotion and government spending, and are important factors in this issue.

Helen clearly stated the major issue facing health and health promotion research that is relevant to the inclusion of people with disabilities, “I think that all research has to be participatory. I think especially working with individuals with disability should be participatory.” This emphasis on community participation cannot just be in the research portion of a project, but also in formulating the questions that are to be answered and how to go about researching them. A lot of academic research is rooted in an older model of researcher-driven questions and methodologies whereby end-users are not part of the design process. Arlene similarly stated the importance of having a truly inclusive research process where people with disabilities are not just

passive participants in research that is being done on them, but are actively investigating the questions and issues they find relevant, using methods that are both sensitive to their needs and effective in creating solutions.

At the root of the issue of inclusive research practices is the way in which disability has traditionally been characterized in health research, namely as a pathology that exists within the individual (Shakespeare, 2008; Martin Ginis & Hicks, 2007). When disability is defined in this way, it leaves the treatment up to medical and rehabilitation professionals, providing little autonomy for the people affected by the disabilities. Helen and Arlene advocate for a more balanced view of disability, where social constructs and barriers are taken into account, as well as psychological barriers that often hinder participation in healthy behaviours. The identification of such constructs and barriers, however, hinges on the participation of people with disabilities acting on their own behalf in the research process. While Arlene recognized in her statements that it is not always feasible to have stakeholders from every group present in every aspect of a project, attempts must be made to legitimize and include these perspectives so that the overall research project has validity and can effect real change at the personal and community level.

Claire strongly expressed her opinion that the medical model of disability has no place in common discourse as it disadvantages people with disabilities and prevents them from effectively advocating for important causes that promote their inclusion and equality in Canadian society. Claire and her organization promote a view of disability where self-definition is of the most importance. Claire emphasized that “there is no universal definition of disability. It’s what every person thinks about themselves.” Only once advocacy takes place on a plane where each person is entitled to the services they need, can there be greater inclusiveness and an actualized

state of citizenship for all Canadians, where all are equally able to take part in the various institutions and opportunities available.

The second discourse that was strongly expressed by the study participants, was related to the concept of agency, and specifically agency with respect to making lifestyle decisions about physical activity. Research has shown that people with disabilities tend to express less agency and are less able to exert personal preferences when it comes to physical activity and other healthy lifestyle choices (Dubois & Trani, 2009; Cockerham, 2005). Helen referenced some of the current ParticipACTION materials and their emphasis on obesity and sedentary behaviour among children. Although she stated the importance of those materials, it is important to give people with smaller levels of autonomy more empowerment and clear choices when it comes to making healthy decisions, rather than just giving the same message that you can do it. Helen further argued for the importance of resources such as SCI Action Canada's new resource guide for adults with spinal cord injury as a crucial tool, as it does not just state the importance of physical activity and offer some generic tips, but also references specific resources, and even a help-line, so people can take control over their own behaviour and get started along the path towards a healthy lifestyle. The SCI Action Canada "Get Fit Toolkit" was recently released to the public, after years of funding from the Rick Hansen Foundation and the Ontario Neurotrauma Foundation. Since SCI Action Canada is still in the early part of the dissemination process, it remains to be determined what will be the most effective way to promote the toolkit, and how they will measure its impact on increasing PA among people with SCI.

Although there are no associated materials with the newest Canadian Physical Activity Guidelines, just fact pages, the most recent Physical Activity Guide, released in 2011, did include examples of people who use mobility aids, including wheelchairs. In contrast, the SCI

Action Canada guidelines has its associated toolkit and a supporting website with additional resources. The issue with the inclusion of people with disabilities in the general guidelines, however, is that no references were made to the unique barriers faced by people with disabilities, and people who use mobility aids, in accessing physical activity opportunities and resources. Similarly, the promotional materials distributed currently by ParticipACTION include people who use wheelchairs and other mobility devices, and encourages them to incorporate physical activity into their daily routines.

Claire stated that resources for people with disabilities can come in one of two ways. The resources and information that is directed towards the general population must be accessible and relevant for people with disabilities. There is a need, however, for a separate stream of resources that address the unique challenges and barriers faced by people with disabilities, so that they have the opportunity to access the information they really need, and are not just an addendum to the mainstream resources. Helen echoed this sentiment, but emphasized the additional need for unique dissemination strategies so that the information and resources reach those who need it most.

The third theme that was commonly referenced among study participants concerns responsibility. Participants discussed where the onus of responsibility falls to promote healthy behaviours, and, indeed, advocate in general, for people with disabilities in Canadian society. There is a disputed notion in the critical disability studies literature regarding the role of charities and advocacy groups in developing resources and advocating for people with disabilities (Devlin & Pothier, 2005). While some feel that charities have an important role to play in development and dissemination of resources to those with disabilities, others feel that for society to truly be inclusive, the government, at various levels depending on the issue, must step forward and take

responsibility for ensuring equal rights and access for all, regardless of ability. Doing so includes re-evaluating research priorities of government funding agencies to ensure that there are open avenues for answering important health related questions. Helen and Arlene, as academic researchers, expressed their frustration with some of the research funding bodies in Canada. On the one hand, mention of physical activity can automatically exclude them from one pool of funding, but on the other, mention of disability issues necessitates the use of large randomized samples when applying to another research funding agency. Helen stated unequivocally that when applying to SSHRC, “any mention of the word physical activity and your proposal gets thrown out.” At CIHR, on the other hand, “they want randomized controlled trials,” a difficult method to use among those with disabilities, as discussed by Martin Ginis and Hicks (2005). There is no clear source of funding for research that aims to study, in an in-depth fashion, the experiences of people with disabilities as it effects their ability and opportunity to engage in physical activity. Consequently, a lot of the funding for projects with this goal comes from charities and other private sources of funding, where both the amount and commitment are not as stable as operating grants from the major research funding bodies.

Thomas also mentioned this issue of responsibility as it concerns the funding of his organization that provides opportunities for physical activity for people with disabilities in Canada. He said that there is no clear commitment to program funding from the federal government on a year to year basis, and the organization ends up dependent on private donors to fund many of their initiatives, funding that is also difficult to count on and plan on a year to year basis.

Underlying this issue is the practice that people with disabilities are to be pitied, and treated as charity cases, as stated by Devlin and Pothier (2005), and as expressed by Helen and

Arlene in this study. While there is no obvious solution to this issue, one avenue by which it can be addressed is through clear funding commitments from various levels of government, and by re-evaluating the funding criteria used by the major research funding bodies in Canada. By establishing clear expectations and responsibilities from the government, academic researchers, advocacy organizations and private donors, more evidence-based guidelines will be developed and promoted to the segments of the population that were previously ignored. If the ultimate goal is greater physical activity levels, improved quality of life, and greater overall autonomy among the disabled population, efforts towards addressing specific barriers and highlighting recommendations and ways to be physically active could enhance one's agency.

Limitations

Due to the small sample size used in this study, any generalizations must be limited in their scope. Although reference is made to Canadian society and the Canadian population, only Ontario-based researchers and advocates were interviewed for this study, so generalization to the rest of the Canadian population is not possible. The principle investigator is an individual with a physical disability, and this may have impacted both the data collection and analysis processes.

Conclusion

This research highlighted the inadequacy of current physical activity guidelines and health promotion materials with regard to their applicability and relevance for people with physical disabilities. A number of strategies were suggested by the participating stakeholders, including increased funding for health promotion initiatives targeted to this population, more

inclusive research practices among academic researchers, a more cohesive lobbying effort among activists, academics and those involved in health promotion in the community, and an overall shift towards the recognition of social constraints in hindering physical activity participation, rather than focusing on impairments associated with physical disability.

An important theme that was discussed is the role of strategic partnerships among different stakeholders in order to provide more effective PA resources for people with physical disabilities. The ability and motivation of different organizations with varying strategic goals to work together effectively will greatly impact how this issue will develop in the coming years.

Future Research

More study is needed on the process of developing health promotion materials in Canada as relates to inclusion and equality among all segments of the Canadian population. Although the process of resources development is designed to be both transparent and rigorous (Sharratt & Hearst, 2007), more information concerning the inclusion of people with disabilities in the process will provide valuable information to health researchers and promoters.

Up to this point, the medical and social models of disability have co-existed without much interaction (Shakespeare, 2008). Common ground must be found in order for health researchers to incorporate crucial issues of societal inequality in their studies. There has already been a move among some health research groups in Canada to incorporate more qualitative methodology in their research projects (Latimer, Martin Ginis, & Perrier, 2011), and this practice should be more widely adopted in order to make use of personal accounts of disability and its associated barriers as they relate to physical activity participation.

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Chapter IV

Summary of Findings and Conclusion

The perspectives of both the stakeholders in the field of health promotion for people with physical disabilities, and the end-users with physical disabilities are valuable in any analysis of PA guidelines and promotion initiatives currently available in Canada. My research demonstrated that in my sample of stakeholders and end-users similar views were expressed on the gaps and weaknesses in health promotion and service delivery that hinder efforts to promote physical activity among people with physical disabilities. They also referenced similar themes with regard to the topic of disability and inclusion of people with disabilities in Canadian society. In this concluding chapter, I will outline the major findings from this study, from both the stakeholders and end-users, and point out where practical solutions were suggested from either group. Where the stakeholders and end-users differed in opinion or suggested approach, I will shed light on the communication and dissemination of research and services that is urgently needed in order to effectively reach the end-users. I will also discuss the need for greater advocacy and activism in order to effect and sustain change in the realm of health promotion and PA guideline development.

The summarized findings will be organized by theoretical themes and practical themes. Theoretical themes are the definition of disability, the perception of people with disabilities, and how the concept of citizenship can be applied to people with disabilities in Canada. Practical themes are the effectiveness of current PA guidelines for those with physical disabilities, the improvements needed to make health promotion efforts towards this population more effective, and who bears the responsibility for implementing change in this area in the short and long term.

Following the summary of these findings, I will present future directions in research in this area, as well as overall study limitations.

With the exception of Claire, a disability rights activist, all study participants defined disability in a manner consistent with the medical model of disability, highlighting impaired function and bodily limitations. Claire, in contrast, was adamant that the medical model of disability has no place in modern advocacy, and that addressing the societal constraints imposed upon people with disabilities, rather than a focus on rehabilitation and cure, is the way to further the causes of inclusion and citizenship for this segment of the population. Claire's opinion is in line with the stated mission of her organization, which includes eliminating societal barriers to full inclusion for people with disabilities. The other study participants, though some are involved in health promotion research on disability, and others are end-users involved in advocacy, demonstrated their awareness of the exclusion people with disabilities in Canadian society, but feel more impacted by the functional limitations associated with disability than societal exclusion.

While this finding appears inconsistent with the progress of the disability movement over the past 20 years (Shakespeare, 2008), Albert and Harrison (2006) point out the slow process of adaptation from the medical model of disability to the social model. Advocacy organizations and human rights activists have successfully adopted the language and slogans of the social model of disability, but in both research, advocacy, and among end-users, the medical model of disability, and its associated assumptions, remain the default position.

It is crucially important that research be directed to the implementation of the social model of disability and its focus on human rights and equality for all, regardless of ability. Socially oriented research on disability has shown the detrimental effects the medical model has

had on the cause of furthering inclusion and societal participation among people with disabilities (Shakespeare & Watson, 2010). It is also important, however, to take into account the real impact that impaired bodily function has on people, and not to discount the potential positive impacts of rehabilitation and medical intervention (Crow, 1996). Claire aptly stated that people with disabilities need to be given the chance to decide for themselves what they need. I strongly advocate for research and health promotion to take into account societal constraints, in line with the recommendation of Martin Ginis and Hicks (2007), meaning that the voices and opinions of people with disabilities must not be silenced or minimized.

The perception people have of those with physical disabilities is another area in which the inequality between the able and disabled can be highlighted. The end-users with physical disabilities that participated in this study all articulated the negative perceptions they feel are directed towards them by those who do not have disabilities. Similarly, the stakeholders expressed the need for improvement in this area, stressing the role of education and further research for remedying the unequal balance of power they feel is held by the more able-bodied in society.

Arlene suggested that the stereotype content model is a useful way of measuring the perceptions of the able-bodied towards people with disabilities, where various groups are rated based on perceived competence and warmth. Researchers using this model have found that people with disabilities rate high on warmth, but low on competence, suggesting that the raters do not perceive this population as competition in terms of employment and relationships, but they are pitied to some extent (Fiske, Cuddy, Glick, & Xu, 2002; Louvet, 2007). This result shows that the stated negative perceptions of people with disabilities in society are not only

based on their anecdotal experiences, but that there is an empirically studied unequal balance of power and status held by people who are more able-bodied.

The implication of this finding with respect to the provision of PA guidelines and health promotion is that researchers may feel that while people with disabilities are to be pitied and helped, they may not have the autonomy and will to adopt healthier behaviours, such as physical activity. While some research groups, like the ones to which the stakeholders in this study belong, are trying to combat such stereotypes and develop PA resources for people with disabilities, the slow progress and small research base for their work (Martin Ginis & Hicks, 2005) suggests that there is an inherent tendency among able-bodied people to discount those with disabilities.

The academic arena is only one place in which this scenario is played out. The end-users expressed their frustration with feeling as though they are looked over by people, as Sharon said, or the assumption that since they have a physical disability, they must have an intellectual disability as well, as Judy stated. Helen emphasized the responsibility academic researchers have to adopt inclusive research practices when researching disability issues, so that at least in that setting the balance of power can be shifted towards greater equality. Claire aptly pointed out, however, that in the context of daily life the issue is more complex, requiring investment from the government in terms of universal accessibility, as well as the intervention of advocacy groups to ensure inclusion. The area of health promotion and PA guideline development is only one area in which a greater commitment to equality and autonomy for all is warranted. The unequal power balance between the able and disabled in Canadian society is an issue that transcends various aspects of daily life, lowering quality of life for more than one in ten Canadians (Statistics Canada, 2006).

Academics and advocates must continue to address the power relationships between able and disabled populations with the aim to provide better opportunities for a more inclusive citizenship. Lister (2007) listed four values of an inclusive type of citizenship, which, if in place, would ensure a level playing field: justice, recognition, self-determination, and solidarity.

The stakeholders interviewed all agreed that the ideal of inclusive citizenship has not been achieved in Canadian society to this point. As I stated above, the area of physical activity participation and PA guideline development is only one aspect of this exclusion, but to date it has not received attention from major research funding agencies, such as SSHRC and CIHR. Although CIHR does allocate some funds towards the study of disability, the work of SCI Action Canada, the only group of academic researchers and community partners dedicated to PA guideline development for disability in Canada, has been funded by other sources, including the Rick Hansen Institute and the Ontario Neurotrauma Foundation (SCI Action Canada, 2011).

A renewed commitment to inclusive citizenship is called for in many areas of society. The Federal Disability Reports over the past few years have highlighted many of the programs the federal government has implemented to increase equality and inclusion for people with disabilities. Claire pointed out, though, that as long as supports and accommodations remain after-the-fact innovations, issues of accessibility and inclusion will remain a problem. To realize inclusive citizenship, it is necessary to consult with the various groups in society before the implementation of policy, construction of public buildings, or development of health resources. In doing so, all parties can be assured that their voices will be heard, and that the spaces, policy and resources will be accessible and relevant for all. While at times there is a need for separate streams of resources, care must be taken by policy makers, government ministers, and academic researchers to make sure that the needs of people with disabilities are not an afterthought.

The current PA resources for the general Canadian population include the Canadian Physical Activity Guidelines, developed by CSEP (2011) and various promotional materials developed by ParticipACTION, as part of their mandate as the national voice of physical activity promotion (ParticipACTION, 2011). The stakeholders expressed the view that the current PA guidelines and other promotional materials are an insufficient resource for people with physical disabilities. Similarly, when presented with a copy of the guidelines, the end-users interviewed commented on the general nature of the document, saying that they felt it was irrelevant for their needs, as it does not address any of the issues they encounter in physical activity participation. Martin Ginis and Hicks (2007) made a formal recommendation for the development of PA guidelines for different types of disabilities. They stated that not only do current resources not meet the needs of these population in terms of addressing barriers to their participation, but that the actual exercise prescription found in the guidelines is inappropriate, or even dangerous for people with different disabilities. The development of specific exercise prescriptions for different segments of the population is critical to ensure that everyone is on equal footing with respect to their opportunities to participate in, and knowledge of, physical activity. Additionally, the development of materials, such as videos, pamphlets and websites that complement the guidelines is important so that people can find the guidelines on their own, and not just rely on their healthcare professionals to access them on their behalf.

An interesting difference in perspective between the stakeholders and end-users interviewed is what each group feels are the next steps, or best direction to take, in future health promotion efforts directed towards people with physical disabilities. Helen and Arlene, academic researchers, emphasized the importance of developing PA guidelines for different segments of the population, along with resources to go along with them to facilitate people becoming more

active. The focus of such resources would be exclusively physical activity, and overcoming the barriers faced by various populations in adopting physical activity as part of a healthy lifestyle. All the end-users interviewed, though, appeared less concerned with an abundance of PA guidelines and associated resources, and expressed their desire to see a more holistic health promotion document. Such a document would take into account physical activity prescription, nutrition, psychological health, all geared towards their specific needs.

While the end-users acknowledged that such a project is a long way in the future due to the necessary background research and associated costs, the desire to see health promotion delivered in a more holistic sense is attainable even now. There is a plethora of research available on psychological barriers to physical activity for various populations (Rimmer, et al., 2004; Van der Ploeg, Van der Beek, Van der Woude, & Van Mechelen, 2004), including the conceptualizations of interventions and solutions for these issues (Bock, Marcus, Pinto, & Forsythe, 2001; Lee, Arthur, Avis, 2008). What is lacking is the funding and motivation to initiate such a project. The academic fields of exercise physiology, nutrition, exercise psychology, and sociology of sport and physical activity have remained quite separate to this point. Cooperation and sharing between various fields of research could be a good start towards developing resources that are as effective as possible in promoting not just physical activity, but health lifestyles in general.

More research is certainly needed, in cooperation and collaboration with end-users with physical disabilities, to get a better idea of what exactly such a document would encompass, and how it could be best delivered. In her interview, Arlene pointed out that inclusive research practices are important not only in the data collection stage, making end-users active participants in the study, but also in the formulation of what questions are asked in the first place. This is an

area where the future directions in health promotion research and resource development must be developed by the end-users in order to ensure that effective resources are developed that can impact overall health levels among this population.

The implementation of inclusive research programs and the development of effective resources can only take place if appropriate funding initiatives are established. The critical disability studies literature questions the role of the government, charities, academics, and activists in the formulation and attainment of inclusive and equitable policies in Canada (Rioux & Valentine, 2005). The idea that charities are to take up the main role in advocating for the rights of people with disabilities has been heavily criticized, and there has been an attempt by disability scholars to place the onus of responsibility on government officials and policy makers (Rioux & Valentine; Shakespeare, 2005).

The issue of who bears this responsibility is far from a theoretical concern. The end-users in this study were unsure, or even ambivalent about who exactly needs to bear the responsibility for ensuring equal rights and access for people with physical disabilities. What they were sure about, though, was that a clear framework for advocacy needs to be established in order to further the cause of disability rights in Canada. At this time, the system is perceived as quite fragmented, with different special interest groups playing a role for different segments of the population. The Disabled Women's Network (DAWN), for example, is committed to furthering the cause of rights and inclusion for women with disabilities, while CNIB focuses exclusively on people with vision loss. Even those organizations, such as the Council of Canadians with Disabilities, who claim to represent all types of disabilities and causes, are hampered by the lack of centralized organization within the disability movement as a whole to create momentum and

establish leadership, an issue from the earliest point in the disability movement until today (Shakespeare, 2008).

The implication of fragmented leadership and advocacy in the disability movement is that individuals are often forced to advocate for themselves on specific issues of access and inclusion, as Melanie and Claire mentioned in their respective interviews. Not all people with disabilities have the resources and knowledge to effectively advocate for what they need, and many are left without crucial resources. Physical activity participation is one area in which a lack of clear direction in advocating for accessibility and resources leaves many without opportunities. Sharon mentioned the long waiting list for the accessible gym at the Lyndhurst Centre, a gym that is only open three nights a week, and only to those who have made it through the lengthy process of being accepted into the program. There is certainly a consensus among the study participants that more programs like the supervised Lyndhurst gym would be beneficial for people with physical disabilities, but how to bring about their development is much less obvious.

While the next step for the disability rights movement is still rather undefined (Shakespeare, 2008), there have been a couple suggestions put forward by disability studies scholars that may be a step in the right direction. The establishment of a cohesive identity among those with disabilities, facilitated by the existing umbrella disability advocacy groups, might bring more legitimacy and lobbying power to a segment of the population currently fragmented into various special interest groups (Peters, 2000). Watson (2002) found, however, that such a movement is not supported by people with disabilities who very often do not identify with one another, rejecting the notion that a shared physical experience of impairment links them in some intrinsic fashion. Watson discovered that the reason for this lack of cohesion, is that people feel they will face discrimination, especially in employment, if they self identify as having a

disability. As such, the necessary first step towards establishing a cohesive identity among people with disabilities, for the ultimate goal of greater lobbying power, is to combat the stigma so often associated with disability, and to educate the general population on the importance of inclusion. Judy expressed this exact sentiment, saying that the government has a responsibility towards those with disabilities to provide education about disability to the general population. In doing so, the stigma of having a disability can be removed, and the overall life experience for people with disabilities may be greatly improved.

The stakeholders in this study also hold the government accountable for improving equality and inclusion in Canada, but they feel it has to be done largely through a greater commitment to funding for research and other initiatives geared towards disability issues. Pedlar and Hutchison (2000) articulated the issues that accompany shrinking government budgets towards initiatives that benefit people with disabilities, pointing out that as the government takes less responsibility for this population, private businesses try to capitalize on the potential profits they can make for providing these services.

The conclusion to draw from the opinions of the stakeholders and end-users with respect to the issue of responsibility is that while the government holds the key in terms of policy and funding, a cohesive advocacy group is necessary to lobby the government to make this funding a priority. Further research on the identity politics of people with disabilities is necessary in order to establish a workable framework for such an advocacy group. Until the requisite amount of organization and leadership has been established, there is no political motivation for successive governments to listen to the voices of the fragmented few.

In this summary of findings, I have touched upon the major themes identified in this research project by the groups of stakeholders and end-users interviewed. The overall conclusion

to be drawn from this study is that while some progress has been made in the provision of PA guidelines for people with physical disabilities, such as the guidelines for SCI, there is still a long way to go in this endeavour. Further, the organization of advocacy efforts and the goals and biases of health research must be carefully examined in order to ensure equitable and effective research practices for all parties.

I recommend a shift in focus from physical barriers to accessibility, that focus on impairment and individual pathology, to the more socially oriented study of social and policy related barriers that prevent people with physical disabilities from participating in healthy physical activity. Any resources developed for this population must take those considerations into account in order to be relevant and effective, and should consider the intersectionality of race, gender and class with disability. Research programs that incorporate inclusive research practices into their agenda will be even more effective in creating impactful guidelines and resources.

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Appendix A: Interview Guides

Interview Guide for Stakeholders

1. Describe the current efforts by the Canadian federal government to promote physical activity and other health-related behaviours.
2. Describe the current efforts by other organizations to promote physical activity and other health-related behaviours.
3. To the best of your knowledge, how do Canada's efforts in promoting physical activity compare to other developed nations?
4. Describe how the current resources disseminated by the Canadian government and other organizations meet or fail to meet the needs of the general, non-disabled, population.
5. Describe how the current resources disseminated by the Canadian government and other organizations meet or fail to meet the needs of people with physical disabilities.

(This section to be asked to academic researchers)

6. What are your thoughts on the research priorities of funding bodies, such as CIHR, NSERC and SSHRC with respect to research concerning physical activity for those with physical disabilities?
7. Do you believe that an adequate amount of research is being conducted on this segment of the population?
8. (If answer no) What are some of the reasons why this population is not adequately studied? (Describe stigma of the body) Could bodily stigma of those with disabilities by a possible explanation?

(This section to be asked to members of PA promotion organizations)

9. (Show an example of promotional material developed by the organization the interviewee is associated with) Do you believe that documents such as this, developed by your organization, adequately address the health promotion needs of those with physical disabilities? Why or why not?
10. What do you believe the role of your organization is in developing and disseminating resources to promote PA for those with physical disabilities?
11. What kind of strategies for PA promotion do you believe are effective for those with physical disabilities?
12. Define what is disability. Define what is physical disability.
13. How do you believe individual with physical disabilities are perceived in Canadian society?
14. What are some of the barriers they face in accessing physical activity opportunities and resources?
15. What do you believe are the benefits and drawbacks of the biomedical model of disability, which characterizes disability as a pathology that is within the individual?

16. What do you believe are the benefits and drawbacks of the social model of disability, which characterizes disability as an issue of societal inequalities?
17. Which model of disability, biomedical or social, do you believe provides a better framework for studying and implementing health promotion strategies for those with physical disabilities?

18. Devlin and Pothier (2005) defined citizenship as, “the capacity to participate fully in all the institutions of society – not just those that fit the conventional definitions of the political, but also the social and cultural.”
With this definition in mind, do you believe that people with physical disabilities have achieved full citizenship in Canadian society?
19. Do you believe that a hierarchy exists in Canadian society where those who are more able hold more power?
20. What are the consequences of such a hierarchy?

21. Describe the importance of using inclusive language in health promotion documents.
22. (Show an example of a health promotion document) Do you believe that the resources currently available use inclusive language?

Interview Guide for End-Users with Physical Disabilities

1. What does physical activity mean to you?
 2. What is your current level of physical activity participation? (Administer short form of PARA-SCI)
 3. If you were to look for information on physical activity, where would you go to look?
 4. Do you believe that health care practitioners are an effective resource for this information?
 5. Would you look for resources directed to anyone in the general population, or for resources specifically related to your disability? Why?
 6. What do you know about the Canadian physical activity guidelines?
 7. (Show a copy of the general guidelines) Do you feel that this document is relevant to you? Why or why not?
 8. (Show a copy of the American guidelines for people with disabilities) Do you feel that this document is relevant to you? Why or why not? Is it more or less useful than the guidelines for the general population?
 9. (If interviewee has SCI, show copy of guidelines for SCI) Do you feel that this document is relevant to you? Why or why not? Is it more or less useful than the guidelines for the general population?
10. If you could design your own health promotion document, what would it include?
11. Do you face any barriers in accessing physical activity?
12. (If yes) How would you describe those barriers?
13. How would you define physical disability?
14. How do you believe people with physical disabilities are perceived in Canadian society?
15. (If answer that there are negative ideas associated with physical disability) As a male/female, ethnic minority, hetero/homosexual and as a person with a physical disability, do you feel that you are at more of a disadvantage? Why or why not?
16. Whose responsibility is it to address any inequalities that exist in Canadian society? Government? Academics? Charities? Activists? End-users?
17. What kinds of strategies do you believe would be effective to address these issues?

Appendix B: Para-SCI script

I would like you to tell me about the physical activities you have engaged in during the last 3 days. We will be starting with yesterday and going back 3 days. Please remember, this is a recall of *actual* activities for the 3 days, not a history of what you *usually* do.

Also, keep in mind that physical activity includes any activity that required physical effort. That means I am interested in all of the activities you did in a day including the activities you did getting ready in the morning, at work, around the home and during your leisure time. For example, your day might include activities such as transferring, getting dressed and wheeling to the shopping mall.

I will also ask you to categorize the intensity of each physical activity you did into one of four groups, mild, moderate, heavy or nothing at all. Each of these intensities is described on the colorful sheet in front of you (*review each definition*). Notice that this sheet also provides a description of how you might feel at each intensity of activity.

Setting the Stage

Today is _____ (i.e., Monday), so yesterday was _____ (i.e., Sunday). Think about what you did (Sunday) morning.

Questions and Prompts to Facilitate Accurate Recall

Morning	Afternoon	Evening
<ul style="list-style-type: none"> - What time did you wake up? - After you opened your eyes what was the first thing you did? - What other activities did you do that required physical exertion? - What did you do after your morning routine? - Think about what you usually do. Did you do anything unusual? 	<ul style="list-style-type: none"> - Tell me about your afternoon. - What did you do for lunch? - What did you do after lunch? - Think about what you usually do. Did you do anything unusual? 	<ul style="list-style-type: none"> - What did you do for dinner? - What did you do after dinner? - Think about what you usually do. Did you do anything unusual? - Tell me about your evening routine. - What activities did you do that required you to be physically active?

Intensity and Duration

Using the chart you have been given, how would you rate the intensity of that activity?
How long did you work at that intensity?

At the End of Each day Ask

Are there any physical activities that you might have forgotten?
Did you have to take any trips to the bathroom during your day?
Did you do any physical activity at work?
Any other recreational or sport activities? Housework or gardening?

Morning routine and evening routine day 2 and day 3

Compared with the morning/evening routine you just described (day 1), were there any differences in your morning/
evening routine (day 2 and day 3)? *If no differences, do not go through the morning or evening routine again.*

On the Last Day of Recall Ask

Take a moment to think back over the course of the past 3 days; can you think of any activities that you may have forgotten?

Appendix C: Physical Activity Guideline Materials Reviewed

1. Canadian Physical Activity Guidelines for Adults Ages 18-64
2. American Physical Activity Guidelines: Considerations for Some Adults
3. Physical Activity Guidelines for Adults with Spinal Cord Injury

Canadian Physical Activity Guidelines

FOR ADULTS - 18 – 64 YEARS

Guidelines



To achieve health benefits, adults aged 18-64 years should accumulate at least 150 minutes of moderate- to vigorous-intensity aerobic physical activity per week, in bouts of 10 minutes or more.



It is also beneficial to add muscle and bone strengthening activities using major muscle groups, at least 2 days per week.



More physical activity provides greater health benefits.

Let's Talk Intensity!

Moderate-intensity physical activities will cause adults to sweat a little and to breathe harder. Activities like:

- Brisk walking
- Bike riding

Vigorous-intensity physical activities will cause adults to sweat and be 'out of breath'. Activities like:

- Jogging
- Cross-country skiing

Being active for at least **150 minutes per week** can help reduce the risk of:

- Premature death
- Heart disease
- Stroke
- High blood pressure
- Certain types of cancer
- Type 2 diabetes
- Osteoporosis
- Overweight and obesity

And can lead to improved:

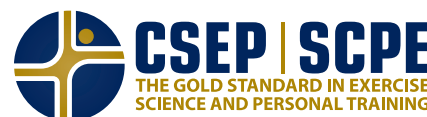
- Fitness
- Strength
- Mental health (morale and self-esteem)

Pick a time. Pick a place. Make a plan and move more!

- Join a weekday community running or walking group.
- Go for a brisk walk around the block after dinner.
- Take a dance class after work.
- Bike or walk to work every day.
- Rake the lawn, and then offer to do the same for a neighbour.
- Train for and participate in a run or walk for charity!
- Take up a favourite sport again or try a new sport.
- Be active with the family on the weekend!

Now is the time.

Walk, run, or wheel, and embrace life.



www.csep.ca/guidelines

American Adult PA Guide – CDA

1. What social event, and what chain of social events, is the text a part of?

This text is part of the larger effort by the American government to promote healthy behaviours among the American population. Associated texts include the full PA guidelines for adults, children and older adults, as well as the American Food Guide.

2. What social practice or network of social practices can the events be referred to, be seen as framed within?

The social practice of healthy behaviours and clinical practice guidelines for promoting those kinds of behaviours.

The larger discourse at work is one of health promotion and the prescription of how to live a healthy life by those in authority.

3. Is the text a part of a chain or network of texts?

Yes, the American PA guidelines.

4. Is the text situated within a genre chain?

Yes – the text is the amalgamated results of many research findings, summarized in the form of guidelines for the general public.

5. Is the text characterized by a mix of genres?

No – it's a straightforward health promotion document developed with the support of the American government.

6. What genres does the text draw upon and what are their characteristics?

Promotional genre – a genre that is mediated for the purpose of 'action at a distance.'

Information is recontextualized from one context to one of promotion in order to effect wide-scale change in the population. The promotional genre is a genre of governance.

7. Orientation to difference:

d. A bracketing of difference, a focus on commonality, solidarity.

Each individual case highlighted in the PA guide has the same opportunities and the same long-term goals of healthy, active living. Even if they didn't realize at first how important it was, once they learned about it, they all adopted the same positive attitude towards PA participation.

8. Of relevant other texts/voice, which are included, which are significantly excluded?

The official document of the American PA Guidelines are referenced as a product of the U.S. Department of Health and Human Services.

No other voices or texts are included.

PHYSICAL ACTIVITY GUIDELINES

for Adults with Spinal Cord Injury



www.sciactioncanada.ca/guidelines

PREAMBLE

These guidelines are appropriate for all healthy adults with chronic spinal cord injury, traumatic or non-traumatic, including tetraplegia and paraplegia, irrespective of gender, race, ethnicity or socio-economic status. Adults are encouraged to participate in a variety of physical activities that are enjoyable and safe.

You should try to be active throughout the day, and in a variety of ways, in addition to your usual activities of daily living.

If you are newly injured, are pregnant, prone to autonomic dysreflexia, or have other medical conditions, you should talk to your health professional to find out what types and amount of physical activity are right for you. A health professional might include a doctor, a physiotherapist, or a qualified exercise professional.

As a safe progression towards meeting the guidelines it is appropriate to start with smaller amounts of physical activity and gradually increase how long, how often, and how hard you engage in physical activity.

For important fitness benefits, adults with a spinal cord injury should engage in:

**At least 20 minutes of moderate to vigorous intensity aerobic activity 2 times per week,
AND**

Strength training exercises 2 times per week, consisting of 3 sets of 8-10 repetitions of each exercise for each major muscle group.

How...?	Aerobic Activity	Strength Training Activity
How often?	Two times per week	Two times per week
How much?	Gradually increase your activity so that you are doing at least 20 minutes of aerobic activity during each workout session.	Repetitions are the number of times you lift and lower a weight. Try to do 8-10 repetitions of each exercise. This counts as 1 set. Gradually work up to doing 3 sets of 8-10 repetitions of each exercise.
How hard?	These activities should be performed at a moderate to vigorous intensity. Moderate intensity: activities that feel somewhat hard, but you can keep doing them for a while without getting tired. Vigorous intensity: activities that make you feel like you are working really hard, almost at your maximum, and you cannot do these activities for very long without getting tired.	Pick a resistance (free weights, cable pulleys, bands, etc.) heavy enough that you can barely, but safely, finish 8-10 repetitions of the last set. Be sure to rest for 1-2 minutes between each set and exercise.
How to?	There are many ways to reach this goal, including: <i>Upper Body Exercises:</i> wheeling, arm cycling, sports <i>Lower Body Exercises:</i> Body weight supported treadmill walking, cycling <i>Whole Body Exercise:</i> recumbent stepper, water exercise	There are many ways to reach this goal, including: <ul style="list-style-type: none"> ■ Free weights ■ Elastic resistance bands ■ Cable pulleys ■ Weight machines ■ Functional electrical stimulation