

**Self-perceived Participation amongst Adults with Spinal Cord Injuries:  
The Role of Assistive Technology**

by

Jacqueline Dawn Ripat

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## Abstract

The purpose of this research was to develop a theoretical understanding of the influences on participation for individuals with spinal cord injury (SCI) from a self-perceived perspective, with particular focus on the role of assistive technology (AT) in self-perceived participation. The theoretical underpinning, symbolic interactionism, was used to gain an understanding of the ways that adults with SCI ascribe meaning to the interaction between themselves and their unique environments in a process of participation.

A grounded theory study of 19 adults with SCI was conducted. Participants engaged in individual in-depth interviews, used photovoice as a framework for taking photographs of aspects of their environment that promoted and restricted participation, and engaged in focus groups. The constructed grounded theory is summarized as follows: *Negotiating the Body-environment Interface* is a continuous process for those living with a SCI. Despite the relative stability of their changed body, they *Live in a Changed World*, one perceived differently after SCI. Four sets of strategies are used by individuals to interact within their unique environments: creating an accessible proximal environment; using AT and adaptations; advocating and educating; and gaining information and knowledge. Strategies were selected to engage in a *Process of Participation*, a process that consisted of a sense of inclusion, autonomy, accomplishment, and reciprocity. Intervening conditions were the physical (architectural, natural), socio-cultural (social

supports, societal attitudes), and institutional (services, policies) environmental aspects that served as barriers or facilitators to the process of participation.

The study has added to the growing body of literature on self-perceived participation that forefronts the sense of connectivity and engagement people feel within their environment. The findings highlighted how AT holds unique meaning, and how decisions around use of technology for participation is influenced by personal factors, and physical, socio-cultural, and institutional environments. A new definition of AT was constructed that acknowledges the environmental influences and importance of self-perceived participation as an outcome of AT use. This research highlights the instrumental role of the environment in supporting self-perceived participation of adults with SCI. Further research on developing ways to create inclusive and supportive environments for assistive technology users is warranted.

**Key words:** self-perceived participation, assistive technology, assistive technology-environment interface, spinal cord injury

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## **Dedication**

*To the Dobson 'girls', Ruth McGill (née Dobson) and Helen Dack (née Dobson)*

*– Who early in the 20<sup>th</sup> century set a high academic bar for women in our family.*

*To the McCartney 'boys'*

*– My life, my inspiration, and to whom I hope to pass on a love of learning.*

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## **Structure and organization of the thesis**

This thesis is organized according to a manuscript style with four distinct, but inter-related manuscripts comprising the body of the findings section. Chapter 1 provides an introduction to this thesis. Chapter 2 includes the overall literature review and justification for conducting this work. Chapter 3 provides an overarching view of the theoretical underpinnings of the study, and outlines the methodology and methods used to conduct the study. Chapter 4 introduces the findings section, followed by the four manuscripts located in Chapters 5, 7, 9, and 11. Between each manuscript, a brief linking chapter is included (Chapters 6, 8, 10) that serves as a conceptual link between the chapters, that outlines the logic in linking these sections, and that describes how the findings or conclusions of the previous manuscript are carried forward, expanded on, or explored in the subsequent manuscript. Chapters 12-14 are again overarching, relating to the entire thesis.

The reader will note redundancies between Chapters 2 and 3 and the introduction and methods sections of the manuscripts found in Chapter 5 and 9. Including this information in each manuscript was required as each was also constructed as a stand-alone and self-contained research report, as is the case in preparation for publication. Consequently, the references for the in-text citations included in the body of each paper are found at the end of the respective manuscript. The references for chapters 1-4, 6, 8, 10, 12-14 are located at the end of this document.

## **Chapter 1: Introduction**

Spinal cord injury (SCI) creates a biographical disruption (Bury, 1982; Hammell, 2004b; Hammell, 2007) in an individual's life course and results in profound lifelong functional implications (Lysack, Komanecky, Kabel, Cross, & Neufeld, 2007). In Canada, 14.3% of Canadians reported living with a disability (Statistics Canada, 2008a). Specifically, an estimated 86,000 Canadians are living with a SCI: this number is predicted to increase to 121,000 by the year 2030 (Farry & Baxter, 2010). Assistive technology (AT) is often used by individuals with SCI to participate in desired occupations when the ability to ambulate or manipulate objects is compromised (Di Marco, Russell, & Masters, 2003). AT includes both the devices used by individuals (e.g. wheelchairs, environmental aids to daily living) and the service provision aspect (assessment, acquisition, funding, user training). Health care professionals have a long history of involvement of AT recommendation and provision as an important part of a complex healthcare process (Hocking, 1999). Historically, recommendations have been made based on clinical judgment and outcomes that focused on the self-evident benefits of AT and 'what works' from the perspective of the individual user or service provider (Fuhrer, 2001). However, rapid advances in technology over the past few decades and the concomitant focus on rehabilitation outcome measurement have made decision-making around appropriate AT more complex.

With the recent emphasis on participation as a principal outcome of rehabilitation, there has been a developing interest in the role AT plays in promoting the ability of an individual to participate within his or her physical and social environment. However,

outcomes research on the role of AT in facilitating participation has been limited by a lack of theoretical basis, outcome measures without a conceptual underpinning of participation, and empirical studies that lack methodological rigour (Arthanat, Bauer, Lenker, Nochajski, & Wu, 2007; Isabelle et al., 2002). Others have argued that viewing the subjective perspective of participating or participation is the more relevant perspective to examine with AT users (Hammel et al., 2007; Harris, 2007). Proponents of this perspective suggest that study of participation must focus on what is meaningful to the AT user rather than on socially dictated norms.

Thus, although improving participation has been identified as the ultimate aim of AT use, understanding the participation experiences of adults with SCI has not been an area of research focus. Furthermore, studying the construct of participation as an outcome of an AT intervention is still in its infancy. There is a need to conduct research targeted at gaining a theoretical understanding of the ways that individuals with SCI participate in daily life, and the role that AT plays in that participation. Thus, the primary purpose of this research was to advance an understanding of how adult Manitobans with SCI participate in daily life, and the role that AT plays in participation, in order to promote opportunity for participation for adults with SCI. The specific research objectives were:

1. To examine the ways that adult Manitobans with SCI participate in daily life.
2. Within the Manitoban context, to identify the individual and environmental conditions that contribute to how adults with SCI participate in daily life.

3. To explore how AT devices contribute to (or hinder) participation in daily life for these adults.
4. To gain an understanding of the experience, and meaning of AT use for adults with SCI.

This work is an essential precursor to development of future participation outcome measures for individuals with SCI. Developing an understanding of, and learning from, adults with SCI who use AT will help AT service providers and policy-makers better meet the needs of this population. Gaining these perspectives will provide essential information to individuals with SCI, families, service providers, funders, and policy makers to ensure that positive opportunities exist for individuals with SCI to participate in their families, communities, and society.

## **Chapter 2: Literature Review**

This literature review will provide an overview on adults and SCI, what is known about participation for individuals with SCI, and the role and meaning of AT as it influences participation. This review provides the rationale behind the premise that studying the self-perceived participation experiences of adults with SCI is a logical and necessary first step to developing a theory of participation and AT for this population.

### **Spinal cord injury and participation**

The term *biographical disruption* (Bury, 1982) has been used to describe how a SCI can affect an individual's life course (Hammell, 2007; Hammell, 2004b). A disrupted biography will have both consequences, in terms of influencing previously experienced roles and routines, as well as significance and value at the individual and social level, in terms of one's self-identity (Bury, 1982; Hammell, 2004a). Approximately 86,000 Canadians are currently affected by SCI and the number of individuals with SCI is predicted to be 121,000 by 2030 (Farry & Baxter, 2010; Rick Hansen Foundation, 2009). It is evident that a large number of Canadians are living with, and will experience in the future, a biographical disruption that holds individual and societal implications.

In the rehabilitation literature, the term participation has been used synonymously with various other terms, including: social adjustment, independent living, social functioning, community integration, and community participation (Cicerone, 2004; Dijkers, Whiteneck, & El-Jaroudi, 2000; Hammel, Jones, Gossett, & Morgan, 2006). It is through participation that individuals gain skills, connect with other individuals and



communities, and discover meaning in life (Law, 2002). Participation “occurs at the intersection of what the person can do, wants to do, has the opportunity or affordances to do, and is not prevented from doing by the world in which the person lives and seeks to participate” (Mallinson & Hammel, 2010, p.S30). Furthermore, community participation involves access to community spaces, activities, and social relationships (Carpenter, Forwell, Jongbloed, & Backman, 2007). The importance of community participation is apparent in the literature; life satisfaction amongst people with disabilities has been more closely related to community participation than to ones’ state of illness or impairment (Carpenter et al.; Whiteneck et al., 2004).

Participation can be understood as either objective (society-perceived) or subjective (self-perceived) (Noreau, Fougereyrollas, Post, & Asano, 2005). Society-perceived participation is based on societal imposed norms of what is expected of individuals of a particular age and culture (Cardol, De Jong, & Ward, 2002; Saadah, 2002). The International Classification of Functioning, Disability and Health (ICF: World Health Organization, 2008) has gained recent prominence for shifting its attention from a disability residing at the individual level to suggesting that the social and physical environment interacts with the individual to restrict societal participation (Harris, 2007; Imrie, 2004; World Health Organization, 2008). According to the ICF, participation is defined as ‘involvement in a life situation’ (World Health Organization). The ICF distinguishes objective involvement from the subjective perspective (e.g. the sense of belonging) and recognizes the former as the object of interest. Although widely accepted as an important classification model in health care, the ICF has received criticism for its

universal categorization of individuals with disabilities that perpetuates professional dominance (Hammell, 2006) and an assessment of the individual and environment that fails to recognize the transactive nature of this relationship (Hammell et al., 2007).

In contrast to the society-perceived perspective is the belief that participation should be defined from the self-perceived perspective; this perspective addresses issues such as the degree of connectivity that individuals with disabilities have with their environment (Hammell et al., 2006). From the self-perceived perspective, the only one who can truly define and understand participation is the individual him or herself (Perenboom & Chorus, 2003) and self-perceived participation is viewed as a process that continues through life rather than as solely an outcome of rehabilitation (Carpenter, Forwell, Jongbloed, & Backman, 2007; Hammell et al., 2006). The self-perceived perspective is consistent with the social model of disability as the latter “emphasizes the lived experience of people with disabilities as reflected in the notions of participation and access to community life” (Harris, 2007, p.138).

Studies among individuals with SCI have predominately used society-perceived perspectives, with limited use of self-perceived perspectives, to explore concepts related to participation. For example, some research has suggested that length of time since injury onset is positively related to satisfaction with community integration (Boschen, Tonack, & Gargaro, 2003) and perceived quality of life (Hammell, 2004b). However, there are discrepancies in studies of perceived participation in adults with SCI and the relationship with life satisfaction, with some identifying a positive relationship (Anderson

et al., 2004; Lund, Nordlund, Bernspang, & Lexell, 2007), while others have demonstrated a limited relationship (Whiteneck et al., 2004). Other adults with SCI have identified that participation is enabled as barriers are removed (Ward, Mitchell, & Price, 2007). Differences in these studies may in part be attributed to the use of outcome measures based on the varying ways that researchers have operationalized societal-perceived participation.

There has been limited research of subjective aspects of participation for individuals with SCI, however in one recent study self-perceived participation of men with SCI during the transition from hospital to home was explored (Van de Velde, Bracke, Van Hove, Josephsson, & Vanderstraeten, 2010). These participants depicted participation as a set of values that included occupying time, achievement, inclusion, and having a sense of control through activity. The authors stressed the need to gain understanding from individuals with SCI with a greater range of diversity, including longer time in the community and augmenting findings with additional research methods beyond individual interviews.

Environmental barriers to participation are well-established in the AT, rehabilitation, and disability literature (Berry, McLaurin, & Sparling, 1996; Shepherd, Stewart, & Murchland, 2007). The contextual congruence, or lack of congruence, between the physical, structural, social, system/policy, and attitudinal environments can create opportunities for participation, or conversely create barriers to participation (Hammel et al., 2008; Hammell, 2007; Skär, 2002). Despite international legislation and

increased societal awareness of the need to have accessible public spaces, many inaccessible public buildings and facilities continue to exist (Brandt, Iwarsson, & Stahle, 2004; Carpenter et al., 2007; Chaves et al., 2004; Dattilo et al., 2008; McMillen & Soderberg, 2002; Meyers, Anderson, Miller, Shipp, & Hoenig, 2002; Skär, 2002d; Swinth, 1997; van de Ven, Post, de Witte, & van den Heuvel, 2008). Natural and climatic environment barriers, such as sand and snow ground surfaces, have also been cited as creating barriers (Boschen et al., 2003; Dattilo et al., 2008d; Hammell, 2007; Lysack et al., 2007; Skär, 2002), and the lack of appropriate transportation has been specifically identified as an environmental barrier for individuals with SCI (Carpenter et al., 2007; Lysack et al., 2007; Whiteneck et al., 2004).

In a study of 136 adults with SCI living in the Detroit area, Lysack et al. (2007) found that for individuals with SCI, fewer barriers in the community were correlated with greater perceived community integration for adults with SCI. In contrast, Whiteneck et al. (2004) found that environmental barriers accounted for a very limited percentage of the variation in participation scores of 2726 adults with SCI. The discrepancy between these findings again may be due to limitations in the quantitative outcome measures used that fail to adequately capture the construct of participation (Lysack et al., 2007). Negative and exclusionary attitudes are also frequently identified as a primary barrier to full societal inclusion for individuals with disabilities (Hammell, 2006; Roulstone, 1998). Researchers report that a lack of social awareness about the challenges faced by people with disabilities and disrespectful attitudes are faced on a regular basis by people with disabilities (Hammell, 2007; Isaksson, Josephsson, Lexell, & Skar, 2007; Meyers et al.,

2002; van de Ven et al., 2008). It is clear from the literature that physical, architectural, and social environment barriers continue to remain an unresolved issue.

### **Assistive technology**

In Canada, AT has been defined as: “all specialized aids, devices or services that enable persons with disabilities to carry out their everyday activities, such as by making it easier for them to get around (wheelchair, hand or arm support) or by helping them to hear, see or speak (hearing aid, Braille reading materials, keyboard device for communicating)” (Statistics Canada, 2008b). In the U.S., AT is defined as: “any piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. (AT service is) any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device” (Tech Act, 1998).

Although the primary focus of both of these definitions (i.e. using AT to improve functional performance) has been frequently supported in the AT literature (Cook & Hussey, 2002; Isabelle et al., 2002; Johnson, Dudgeon, Kuehn, & Walker, 2007; Judge, 2002; Ripat, 2006), others have critiqued existing definitions for not considering how AT might be used to enhance social functioning (Edyburn, 2003). Correspondingly, there has been the shift in the AT lexicon over the past two decades, from describing AT’s primary purpose in terms of remediation of an individual’s impairments, to discussing how it promotes ability to engage in activity, to the current emphasis on the social aspects of

functioning that can be realized through AT use. Recently, AT has been described as promoting individual empowerment (Hutzler, Fliess, Chacham, & Van den Auweele, 2002), providing a means to circumvent barriers in the environment (Louise-Bender Pape, Kim, & Weiner, 2002), providing the possibility of “achieving a better life” (McMillen & Soderberg, 2002, p.177), and increasing participation (Campbell, Milbourne, & Wilcox, 2008; Copley & Ziviani, 2004; Jirikowic, Rickerson, & Burgstahler, 2003).

Contributing to the role of AT in promoting or creating barriers to participation is the service delivery (Tam, Archer, Mays, & Skidmore, 2005). Barriers identified in the literature that relate to the service delivery processes include: a lack of a team approach, assessment processes that lack consideration of the environments of AT use, lack of appropriate funding for the technology, lack of information on availability of devices and services, and lengthy wait times to receive devices (Brodin et al., 2001; Copley et al., 2004; Dattilo et al., 2008; Lindstrand, 2002; Ostensjo, Carlberg, & Vollestad, 2005; Phillips & Zhao, 1993; Routhier, Vincent, Morissette, & Desaulniers, 2001; Wessels, Dijcks, Soede, Gelderblom, & de Witte, 2003). It is obvious that the AT service delivery process itself often prevents users from accessing the AT that they need and want.

Of the 75,380 Manitobans aged 15-64 who reported a disability in 2006, 44% reported using adaptive aids or equipment. Furthermore, approximately 20% of Manitobans with reported disabilities in the same age range (14,830) reported unmet needs for assistive devices, primarily related to cost, lack of availability or lack of

awareness of where to get the device (Statistics Canada, 2008b). Assistive technologies such as manual or powered wheelchairs are frequently used to enable an individual with a SCI to participate in desired occupations when the ability to ambulate is compromised (Di Marco et al., 2003). Although statistics specific to individuals with SCI are not readily available, 70% of individuals with SCI reported using AT for mobility in one cross-sectional study of 157 individuals (Lund et al., 2007). Some research findings have supported AT as one of the greatest facilitators for individuals with disabilities (Boschen et al., 2003; Dattilo et al., 2008; Swinth, 1997). For instance, in a survey of 357 members of the British Columbia Paraplegic Association, 20% identified AT as one of the primary supports for participation in social and community activities (Carpenter et al., 2007). In contrast, numerous other studies have asserted that specific features of the technology create barriers. For example, the increased demands on time related to AT use and the complexity of devices have been reported to create difficulties for the users (Copley et al., 2004; Dattilo et al., 2008; Lindstrand, 2002; McMillen & Soderberg, 2002; Ostensjo et al., 2005; Phillips et al., 1993).

The meaning afforded by the user to a particular AT device has been suggested as important and influential of a factor as the skill of the user in determining use or non-use (Louise-Bender Pape et al., 2002; Lupton & Seymour, 2000; McMillen & Soderberg, 2002; Spencer, Emery, & Schneck, 2003). Assistive devices are closely integrated in the human-world relationship and are not simply objects (Pettersson, Berndtsson, Appelros, & Ahlstrom, 2005) and thus hold meaning to the individual users. Personal and socio-cultural factors related to AT meaning and use have been highlighted in the literature as

influencing the meaning ascribed to AT (Louise-Bender Pape et al.). Personal factors include issues of identity, the affective response to use of AT, and the individual's perspective on the usefulness or purpose of the AT (Hocking, 1999; Swinth, 1997; Toombs, 1995). Issues of identity have been suggested to play an important role in determining whether one decides to use the AT and in what context (Hocking). Identity is a complex phenomenon that Hocking suggests encapsulates both psychosocial and cultural influences that affect the AT user. Some people assign a symbolic value to AT (e.g. a symbol of improvement or decline, a stigmatizing symbol or a tool of competence and capacity) defined by social and cultural norms. How AT contributes to identity may take several forms (Kinavey, 2006; van de Ven et al., 2008): it may be integrated into one's sense of self and serve as an extension of the body (Goberman-Hill & Ebrahim, 2007; Louise-Bender Pape et al.; Skär, 2002; Toombs) or alternatively it may serve as a symbol that sets the person apart from others (Goberman-Hill & Ebrahim; Skär).

### **Assistive technology and participation**

The integration and dynamic interaction of the person, environment, and AT is well-accepted in the field of AT as a framework for selection of, and predicted successful use of, AT (Cook et al., 2002; Fuhrer, Jutai, Scherer, & DeRuyter, 2003; Scherer & Craddock, 2002). Furthermore, Noreau et al. (2005) propose that the interaction of these three factors also play a role in self-perceived participation. Decision-making frameworks that provide guidance on appropriate AT selection and successful AT use are essential for service providers who are involved in identifying functional problems, determining



appropriateness of the AT in addressing those issues, and improving service delivery and provision (Tam et al., 2005).

Historically, recommendations and decisions have been made based on clinical judgment and outcomes that focused on the self-evident benefits of AT ‘what works’ from the perspective of the individual user or service provider (Fuhrer, 2001). However, the rapid advances in technology over the past few decades have made decision-making more complex and the development of outcome measures used in AT has been slow to develop relative to other areas of rehabilitation. In a review of 100 commonly used rehabilitation outcome measures, only 23% allowed a maximal score to be achieved with the use of AT and only three measures identified the independent effect of AT (Rust & Smith, 2005). Despite the intended benefits of AT, clear relationships between the intended and resultant impacts have yet to be established.

Although it is most often assumed that AT use has a positive effect in promoting participation (Harris, 2007; Jirikowic et al., 2003), a paucity of research exists that explores this assumption. In a review of the literature examining the effect of AT on participation since 2001 (when the International Classification of Functioning, Disability, and Health) was first published), few outcome studies were located that have investigated the role of AT as the intervention in improving ability to be involved in a life situation, or participate (Gentry, Wallace, Kvarfordt, & Lynch, 2008; Jedeloo, de Witte, & Schrijvers, 2002; Pettersson, Berndtsson, Appelros, & Ahlstrom, 2005b; Tam et al., 2005; Vincent, Deaudelin, & Hotton, 2007). Of the studies published and reviewed, definitive

conclusions on the role of AT is not possible due to heterogeneity in the population (age, disability), type of AT used, and the use of outcome measures that were not developed with a theoretical basis specifically on the construct of participation.

More recently, a few AT outcome measures have been developed that address societal-perceived frameworks of participation (Gray, Hollingsworth, Stark, & Morgan, 2006; Mortenson, Miller, & Auger, 2008; Noreau, Fougereyrollas, & Vincent, 2002). However, by constructing society-perceived perceptions of participation only, Clapton and Kendall (2002) warn that we will “conceal the structural elements of the political context that allow hegemony and oppression to continue” (p. 990) and Brown et al. (2004) argue that using an objective measure of participation only is an “injustice to the values and goals of the person served” (p.462). Thus, developing an understanding of self-perceived participation for individuals with SCI is paramount to the development of relevant outcome measures (Lysack et al., 2007), and qualitative research is required to better understand the role of AT in the lives of individuals with SCI and the influences AT has on opportunities to participate.

### **Significance**

It is apparent that the complex interaction of physical and sociocultural environmental, technical, and personal characteristics results in a variety of outcomes where the AT may serve as either a facilitator or barrier to participation and further understanding of the interactions is required (Carpenter et al., 2007; Pettersson, Berndtsson, Appelros, & Ahlstrom, 2005). However, a specific understanding of the

interaction of these elements on self-perceived participation for adults with SCI who are AT users has yet to be developed. Although there is some emerging understanding of aspects of self-perceived participation among individuals with SCI, there is a pressing need to develop a more comprehensive understanding of how environmental barriers influence participation for individuals with SCI. It is clear that quantitative measures based on objective assessment, injury level, or ability to complete an activity cannot take into account the contextual nuances or social locations of individuals that impact their participation (Lysack et al., 2007). Although improving participation has been identified as the ultimate aim of AT service delivery, understanding how AT devices and services support or limit participation of adults with SCI is not yet clear. In Manitoba, the findings and recommendations emerging from this study will directly contribute to improving the participation experiences for adults with SCI by providing information to individuals with SCI, families, service providers and funders that can inform policy and ensure that the AT devices acquired promote the opportunity for participation in families, communities and society. Nationally and internationally, the theory developed in the context of this study can be used for informing the development of outcome measures based on theoretical understanding of the self-perceived experience of participation for individuals with SCI. The findings of this study will form the foundation for fundamental future research directions that focuses on promoting full community participation for adult Manitobans with SCI. In sum, gaining this knowledge is paramount to supporting the full inclusion and participation of individuals with SCI in today's society, and in the future.



### **Chapter 3: Theoretical perspective, methodology, and methods**

#### **Guiding Conceptual Framework**

This study was theoretically guided by symbolic interactionism (SI). SI assumes that humans act in a way consistent with the meaning they ascribe to a situation (Berg, 2001). This interpretive approach suggests that the meaning ascribed to society and reality are a construction of interaction between the individual and the social structures that are a part of their life-world (such as families or communities) (Berg; Prus, 1996) and that meaning is developed through the dynamic and interactive relationship between individuals and society (Charmaz, 2006). From a researchers' perspective, it is through naturalistic inquiry of inter-subjective experience and inductive analysis that one can come to understand this meaning (Patton, 2002; Prus). Language develops and is shaped by the communities in which people live and thus language and communication are the primary ways of understanding this interaction (Berg; Dietz, Prus, & Shaffir, 1994; Prus).

Symbolic interactionism provided the most appropriate framework for the study for several key reasons. First, individuals with SCI engage and interact on a daily basis with their families and social networks, and within educational, health and community environments. SI provides a framework for understanding the experience of people as interactive within these social structures. In this study, the participants were involved in various social environments and created meaning based on their interpretations. In the research, we sought to understand the inter-subjective experience through opportunities to share that experience, as permitted by the participants, using in-depth and repeated interviews. Second, AT devices are objects that hold unique meaning to the individuals

who use them. Individuals with SCI used AT in the context of their interactions with their social and physical environments and thus the meaning ascribed to that device was believed to be shaped by their inter-subjective experiences. The assigned meaning of AT was anticipated to hold both unique and shared meanings for participants, influenced by the environments and events that people experience as individuals and as a part of community life (Berg, 2001; Dietz et al., 1994). Third, a premise of SI is that individuals uniquely define and attach meaning to their activities; in the current study, the focus on lived and subjective experience thus formed the basis of self-perceived participation. The focus on subjectively defining participation was consistent with the SI tenets regarding activity, where activity is experienced and assigned meaning through subjective experience and environmental interaction (Dietz et al.; Prus, 1996).

Thus, in order to gain an in-depth understanding of the self-perceived participation experiences of adults with SCI who use AT, this study was a qualitative inquiry. Individuals who experience a phenomenon are the appropriate informants on their own thoughts and feelings, and the qualitative paradigm was the most useful for eliciting these thoughts (Woodgate, 2001).

### **Methodology**

Grounded theory as described by Charmaz (2006) was used as a means to understand social processes and structures and to develop theory related to an understanding of the participation experiences of individuals with SCI who use AT. Grounded theory was used to elucidate the phenomenon of AT use for participants, in

terms of their experiences and opportunities to participate in families, communities, and society. Charmaz's description of grounded theory assumes that it is the interaction between the researcher and the participant that produces the data, i.e. as all interactions are dynamic, the individuals involved create and interpret the meanings of these interactions. Correspondingly, a theoretical understanding of the categories, relationships between categories, causes, conditions, and consequences of the phenomenon was sought in this study.

As the construction of the grounded theory is influenced by the researchers' interactions with people and their perspectives (Charmaz, 2006), theory developed from the study of the phenomenon is interpretive in nature rather than conclusive. Thus, the concept of reflexivity in the researcher was of utmost importance. Reflexivity was defined as "thoughtful, conscious self-awareness" (Finlay, 2002, p.532), where the researcher considered her biases, assumptions, actions and inactions during the interview and analysis processes. Through reflexivity, the student researcher explored how she impacted on the research process, and how the research process influenced her. The defining features of grounded theory incorporated into the current study, and described in subsequent sections, included: concurrent data collection and analysis; theoretical sampling; codes and categories that emerged from the data; analytical note-taking; and the construction of a proposed theory that explained the core phenomena and processes.

## **Methods**

### **Recruitment and Sampling Strategies**

Participants were recruited from a wide range of organizations and facilities where adult Manitobans with SCI received services or supports (Appendix A). Letters of invitation that described the study (Appendix B) were circulated via the respective organization's communication systems (e.g. handed out to consumers or members, posted on bulletin boards, inserted into newsletter: Appendix C). Recruitment materials informed potential participants about the study and provided the researcher's name and contact information.

Initial sampling strategies were used to ensure that participants were varied with respect to gender, age, rural vs. urban-dwelling, socio-economic status, length of time since injury and type of AT used. Subsequent sampling attempted to use methods consistent with theoretical sampling to select participants in accordance with the emerging or developing theory and to ensure diversity of opinions and experiences (Charmaz, 2006; Coyne, 1997; Speziale & Carpenter, 2006). Sampling was conducted with the intent of inviting participants whose data would assist with explicating and elaborating on the properties of a category, developing and clarifying relationships between categories, and identifying the processes in existence. The data generated and saturation of category properties achieved through constant comparative analysis dictated the final sample size. Thus, although it was originally anticipated that a minimum of 12



participants would be recruited, the final number of participants informing the study was 19.

### **Participants**

Primary informants in this study were adults with SCI due to trauma, disease, or congenital conditions. Participants ranged in age from 20-60 years (mean = 41 years), 6 (32%) were female and 13 (68%) were male, all were Caucasian, and were residents of Manitoba. All individuals recruited for this study had typical cognitive development for their age and the ability to engage in in-depth interviews. Primary informants were users of a minimum of one AT device as a primary augmentation or replacement of daily function (e.g. canes, manual or power wheelchair) for a minimum of one year.

### **Data Collection**

A blend of three data collection methods were used in this study: collection of socio-demographic information, primary informant interviews (individual and focus group), and photovoice. Woodgate and colleagues have found that the combined use of interviews and photos provides an informative and compelling way to develop an understanding of self-perceived participation in families of children with complex care needs (Woodgate, Hallman, Ripat, Borton, Rempel & Edwards, 2008; Woodgate & Ripat, 2011; Woodgate, Ripat, & Edwards, 2011) and First Nations families who have children with disabilities (Woodgate et al., 2009).

### **Socio-demographic information**

Following receipt of informed consent, a socio-demographic information form was used to guide the gathering of pertinent participant information, for example nature of injury, types of AT used, educational, employment, social status, and community environments (Appendix D).

### **Interviews**

In-depth, intensive individual interviews were held with all participants. The intent of the interviews was to gather rich and detailed descriptions of the meaning of self-perceived participation, and to understand participants' experience of using AT to participate in their lives, homes, and communities. Interviews were held in a location of the participants' choosing (e.g. research facility, health care facility, or participant's home). Each interview was digitally audio recorded.

It was planned that each participant would be interviewed on a minimum of two occasions with further interviews conducted at the discretion of the participant, or if further clarification was required. The purpose of the first interview was to gain an initial understanding of the participant's background and current living situation, to inquire about how the participant conceptualized participation, and to learn about the role AT played in self-perceived participation. The initial semi-structured question route was developed based on the literature, and the student researcher's expertise in AT service provision and in conducting qualitative interviews (Appendix E). The initial question route addressed issues related to experience of disability, experience and history of using

AT, meaning and experience of participation. The question route was refined and narrowed as the study progressed to follow developing theoretical categories that emerged through the constant comparative method of simultaneous data collection and analysis. Questions were sequenced to ensure that any questions that might evoke a stronger sense of emotion were asked later in the interview and after a level of trust and rapport with the interviewer had been established (Dashiff, 2001). At the conclusion of each interview, after the participant had departed, the interviewer took detailed field notes to describe the context of the interview, personal perception of the interview and description of the participant's non-verbal behaviours, communication processes, emerging ideas, and areas required for follow-up. Nineteen participants engaged in the initial interviews; each interview lasted from 75-120 minutes.

### **Photovoice**

Photovoice was used to capture the insider perspective on self-perceived participation. Photovoice is a participatory research data collection method whereby participants inform researchers of community assets and deficits using self-selected photographic images (Strack, Magill, & McDonagh, 2004; Wang & Burris, 1997). It has been suggested as an appropriate means of gathering data from participants with little money, power or status, as may be the case for some adults with disabilities (Strack et al.). The visual images captured by the participants serve as an empowering and creative tool for generating discussion on issues of importance to the participants (Jirikowic et al., 2003). In the current study, participants captured photographic images that were first used to promote dialogue with the interviewer.

At the conclusion of the first interview, information on the photovoice process was discussed, including issues of gaining photographic consent, privacy, and ownership of photos, camera accessibility, and photo techniques: these ideas were reinforced in a handout provided to each participant (Appendix F). Each participant was then provided with a digital camera, either immediately following the initial interview if no accessibility issues were identified, or in a follow-up session if adaptations were required. Some participants required selection of specific commercially available equipment so that it was usable to them (such as larger, non-recessed shutter buttons) while other participants required mounting devices, or adaptive switches. In consultation with a rehabilitation engineer, individualized assessments were completed with each participant and subsequently cameras were purchased and/or modified to ensure independent use of the camera. A table of the selected cameras and adaptations used for each participant in this study is available in Appendix G.

The photovoice data collection consisted of asking participants to photograph relevant individual, family, and community life experiences that illustrated their participation experiences in their home, family, workplace, school, or community. Each participant was asked to select 10-15 photos that best represented their participation experiences. Between the first and second interviews, participants were contacted to determine if they would like assistance downloading, selecting, editing, and creating captions for their digital pictures. Upon their request, four participants were provided with this assistance.

A second interview was scheduled between one and four months after the first. At the second interview, the data gathered by the participants through photography was used to focus and direct the interview using the SHOWED method (Dahan et al., 2007), a technique that focuses on the meaning of the photos to the participants and encourages discussion of action related to perceived injustices. In this interview, the focus was on learning how the participants assigned meaning to the photographs taken, and on understanding their reasons for taking and selecting the particular photos. Fifteen of the original nineteen participants selected and shared photographs in this manner.

Subsequent to the second interview, participants were invited to a focus group to discuss, verify and elaborate on the study findings, engage in critical dialogue about their participation experiences and to discuss future actions that could occur as a result. In the focus group, participants were asked to discuss possible methods of knowledge translation of the photographic images as a means of participant empowerment. A semi-structured interview guide (Appendix H) and PowerPoint™ presentation that depicted the photovoice findings was used during the focus group; the focus group discussion was digitally audio recorded. Two focus groups were held: one participant attended the first, and seven participants attended the second. As several participants had indicated a desire to attend but were unable to attend due to inclement weather conditions, a Photobook (Appendix I) was subsequently developed and sent to five additional participants. Telephone interviews were held with these additional five participants using the focus group questions. The telephone interviews were also digitally audio recorded.

## **Data Analysis**

### **Demographics**

Socio-demographic information was transcribed into an electronic format.

Descriptive statistics on the demographics of the adult participants were recorded and calculated using Excel™.

### **Interviews**

Digitally recorded interviews were transcribed verbatim and hand written field notes were transcribed into an electronic (Word™) format; all identifying information was removed upon creation of the electronic format. Photographic data was uploaded into .jpeg format.

Hard copies of the transcripts were subjected to repeated readings to gain a sense of the whole, and to discern the story line and narrative of each participant, with an aim to “make fundamental processes explicit, render hidden assumptions visible, and give participants new insights” (p.55, Charmaz, 2006). Throughout the analysis, a constant comparative method was used to compare newly collected data with previously collected data, compare collected data to emerging categories, and examine data for developing relationships between categories. In this study, this included comparisons: 1. within an individual transcript; 2. between interviews (intra- and inter-participant) and; 3. with new data as it was collected and included in the study.

The first interpretive move undertaken in analysis was in initial coding, where a process of naming or labeling short segments of text within each transcript occurred,

using gerunds wherever possible to identify the process in existence (Charmaz, 2006). Analytic ideas that emerged during the initial coding were manually recorded on the right side of the transcript and used to question subsequent interview transcripts. Next, a process of focused selective coding ensued, or the selection of the most significant and relevant codes to begin to “sort, synthesize, integrate, and organize large amounts of data” (Charmaz, p.46). Overall, topical themes were pulled from each of the interviews, resulting in an intra-interview thematic analysis. This analysis was conducted through a process of posing and answering the question: Which thematic topics were most important and relevant to the participant in the interview? This process resulted in the development of a focused coding summary for each participant.

The focused coding summary of each participant was compared between participants as each new participant entered the study, and as his or her data was added to the overall data. This process resulted in a combined analysis of focused coding, where the focused codes no longer were related only to an individual participant, but to the participants as a group.

Through a process of memo writing, and re-reading of the combined analysis, some focused codes were raised to the level of categories, or conceptual groupings of codes, and used to define generic processes (Charmaz, 2006). Here, the focus was turned to constructing “generalizable theoretical statements that transcend specific times and places; and contextual analyses of actions and events” (Charmaz, p.46). The analytic

focus moved away from the details that participants presented in an to attempt to discern the core phenomena and processes in existence.

Throughout the analysis, specific attention was paid to in-vivo codes (Charmaz), or the short hand terms or phrases that represented an experience. These codes aided in constructing and explicating analytic categories. For example the term “whirlwind” was used by a participant to describe the time after SCI, when the person returned home. Here, he described experiencing a different and altered embodied self while at the same time the environment he returned to was the same as prior to his injury, creating a feeling of turmoil and loss of autonomy. Eventually, repeated recognition of this experience in the individual interviews led to the core phenomenon depicted in the study findings. Another participant used the term “it only takes one bad apple” to describe how the negative, hurtful, condescending, patronizing or ignorant comments or attitudes would stand out in her mind, regardless of the fact that the majority of their experiences within society were positive and supportive. This became the basis for developing an analytic understanding of how participants were shaped by the power of these occasional, yet significant, words and actions and resulted in one of the categories of intervening conditions.

As the categories emerged, a constructivist approach to theory development was taken, emphasizing development of an advanced understanding of a phenomenon rather than an explanation (Charmaz, 2006). The resultant grounded theory is intended to describe concepts that specify conditions, conceptual relationships, and consequences at



an abstract and general level. Recruitment was concluded when theoretical sampling resulted in category saturation, i.e. when interviews provided no new information in theory development: this occurred after the 19<sup>th</sup> interview. Focus group and follow-up interview transcripts findings were added into the analysis at the conclusion of the individual interview analyses, with intent to further elaborate on or explicate the emergent categories, however while the inclusion of focus group/follow-up interview data was useful in theory refinement, the addition of this data did not create a substantial change to the developed theory.

A series of tables was developed as the categories were constructed to aid in the process of theoretical coding. Several key questions were asked of the data to begin theory construction. For example: What is the primary phenomenon in existence in this analysis? What are the key processes at work? How does self-perceived participation factor into the theoretical rendering? What strategies do people engage in as they engage in their communities? And what prevents and promotes participation? A model was developed and continuously refined throughout this process to conceptualize and relate the categories. Finally, pertinent literature was re-read, with additional sources sought as needed, to examine how the study findings related to, or differed from existing literature. Modifications to the final theoretical rendering of self-perceived participation resulted from discussion with, and feedback from, peers and experts, and re-review of the literature.

### **Measures to Enhance the Rigour and Trustworthiness of the Study**

Issues related to credibility, dependability, confirmability, and transferability were addressed throughout this study (Law & MacDermid, 2008). Through prolonged engagement in the topic area, the researchers and the participants (in the focus groups), were able to engage in further reflection and development of the findings in order to address issues of credibility and dependability. At the point of each major analytical move (transcripts to codes, codes to categories, categories to theory construction), the student shared the findings and her interpretation with her advisor, as well as with three to four peers who held expertise either in qualitative methods of inquiry and/or working with individuals with spinal cord injuries as rehabilitation professionals.

Confirmability of findings was addressed through development of an audit trail, or a recording of the researcher's thoughts, decisions, and actions throughout the data collection and analysis process (Patton, 2002). Providing thick, rich, descriptions of participants and reporting of data using the participants' voices was used to address issues of transferability (Law & MacDermid, 2008). The student researcher attempted to maintain reflexivity, or a self-reflection on prejudices, history, motivations, biases, actions and inactions throughout the research, through documentation in a research log and juxtaposing this reflection against the data collected throughout the analysis process (Cocks, 2006). This was deemed to be particularly important as the student is an occupational therapist researcher with a background in assistive technology and an interest in modifying environments to promote occupational engagement. Discussion with the student's advisor and peers, detailed probing with participants who held

differing views than those of the interviewer, extensive field notes, and repeated review of transcripts prior to subsequent interviews were used as methods to address reflexivity.

### **Ethical Considerations**

Throughout the study, emphasis was placed on ensuring that ethical standards were maintained throughout the project, in particular with attention to respectful interactions that protect the well-being of research participants. The study was approved by the University of Manitoba Health Research Ethics Board (H2009:165) and all participants had an opportunity to ask questions about their involvement in the study prior to consenting to being involved. All participants provided informed consent (Appendix J) prior to initiating data collection. As the data collection occurred over a prolonged period (up to 12 months for some participants), a process of reaffirming consent was used to ensure participants' interest in continuing. As a result, some participants chose not to continue the study after completing the first or second interview (n=19 completed the first interview; n=15 completed the second interview; n=13 contributed to verification of the findings).

In recognition of participants' investment in the study, participants received a \$20 honorarium for participation in each of the interviews or focus group. As the camera modifications were individualized, participants kept their camera at the study conclusion.

## **Chapter 4: Introduction to Findings**

The following section is comprised of four manuscripts that present the primary findings of the thesis. The first manuscript, reported in Chapter 5, examines at a broad level how individuals with SCI describe the process of participating in their lives and communities, and highlights the various aspects of the person and environment that contribute to this self-perceived participation. The remaining three manuscripts (Chapters 7, 9, 11) examine assistive technology as one of the four sets of strategies that support self-perceived participation. The second two manuscripts (Chapters 7 and 9) present an in-depth exploration of how socio-cultural factors influence personal meaning ascribed to assistive technology, while the final manuscript (Chapter 11) broadens back out to a societal level, discussing ways that the assistive technology-environment interface can and should be explored.

Chapter 5 presents the central findings of this thesis. Using symbolic interactionism as an overarching theoretical perspective for this study was integral to interpreting the findings as viewed from the individual AT user. In this study, priority was placed on understanding the meaning ascribed to self-perceived participation constructed by individuals as they engaged in their personal and community environments. This meaning was shared with the researcher through interviews and description of self-selected photographs. Although the meaning of AT was conceptualized as a key concept at the outset, through analysis it became clear that AT was only one of several sets of strategies that individuals used in the process of participation. Thus rather than maintaining a sole focus on the role of AT, a broad set of

strategies are described in Chapter 5 with AT assigned equal, but not greater, emphasis than the other strategies. In this report, a theoretical rendering of self-perceived participation amongst individuals with SCI is depicted in a model. The report concludes with recommendations for potential areas of influence for health care providers when working with people with SCI at the individual (micro) and societal (macro) level (Burbank & Martins, 2009).

In Chapter 7, a selective focus is taken on gaining an understanding of how socio-cultural factors shape AT meaning for the AT user. This manuscript presents a critical examination of the literature on how AT meaning is constructed, and the role that culture (broadly defined as the sets of belief and value systems that shape behaviour) of AT users, families, and service providers plays in ascribing this meaning. This manuscript concludes with recommendations on how AT service providers and researchers can forefront a socio-cultural perspective as they work with AT users.

The content of the first two manuscripts (Chapters 5 and 7) formed the foundation for the development of the third manuscript (Chapter 9), which continued the focus on AT and meaning in the context of self-perceived participation. In this report, the data collected and presented in Chapter 5 on the strategy category of AT (as discussed by participants with SCI and depicted in their self-selected photos) is deconstructed and examined in detail. This paper concludes with a proposed new definition of AT that expands beyond the current focus on the role of AT to improve function. The new contemporary definition addresses the link between AT and self-perceived participation,

and is in keeping with spirit of the role of AT put forth in the United Nations Convention on the Rights of Persons with Disabilities (Borg, Lindstom, & Larsson, 2009; United Nations, 2007).

Using symbolic interactionism as a theoretical framework, in sequence with photovoice, a method founded on “critical consciousness, feminist theory, and documentary photography” (Wang & Burris, 1997, p.370) permitted an in-depth understanding of both the micro and the macro-level interactions between person and their environment as it pertained to their experience of participation. At the micro level, the photos were used in the context of individual interviews as a means of sharing the lived experiences of each participant. The focus on lived and subjective experience formed the basis of self-perceived participation where activity was experienced and assigned meaning through interaction within the environment (Dietz, 1994; Prus, 1996). The insider perspective stresses that what is perceived as a barrier or support “varies across insiders because it is shaped not by the fact of disablement per se but by that fact filtered through the person’s experiences, values, and beliefs” (Brown, 2010, p.S34) and thus by self-selecting and sharing their photos, participants provided insight into their insider perspective. The interviews guided by the photos provided an enhanced understanding of how participation was perceived in the context of self-selected actions or activities.

However, in the focus group/follow-up interviews at the conclusion of the study an additional layer was added: the purpose of the photos shifted from solely

understanding individual meaning towards exploring the photos use in an emancipatory manner consistent with the critical perspective put forward by the social model of disability (Oliver, 1998). The environmental barriers and supports that had been collectively identified and photographed by participants were grouped and shared (Appendix H and I). In the focus group discussions, participants were asked to provide recommendations that could address the environmental barriers to participation they had collectively identified.

Thus, the first three manuscripts set the stage for the final manuscript (Chapter 11), where the literature was examined to uncover the potential the social model of disability and emancipatory disability research framework may have in addressing the environmental barriers highlighted by AT users. This manuscript provides support for adoption of emancipatory principles and approaches in various aspects of AT, including in the conduction of research, development of new technologies, and provision of AT services. The manuscript concludes by proposing a dual perspective on addressing the AT user-environment interface, not focused on the individual AT user (micro) or solely on environmental and societal (macro) barriers, but rather supports the need to examine the two as co-existing and interacting. This complementary view is a prerequisite for the development of innovative strategies to support AT users at individual and societal levels (Burbank & Martins, 2009) and provided the groundwork for the knowledge translation strategies and future research described in Chapters 12 and 14.

In summary, this dissertation moves from the micro/individual level to the macro/societal level and back, enforcing the need to examine both of these aspects, as well as the interaction between them. This comprehensive view is needed to best understand the meaning of self-perceived participation, the role that AT and the AT-environment interface plays in this self-perceived participation. Importantly, this work lays the groundwork for future research, clinical practice, and social action intended to promote self-perceived participation amongst AT users.



## **Chapter 5: Participation amongst adults with spinal cord injury: A grounded theory study**

### **Abstract**

Introduction: Participation has been identified as the foremost aim of the rehabilitation process for individuals with disabilities. Studies among individuals with spinal cord injuries (SCI) have predominately used society-perceived perspectives of participation. A comprehensive theoretical understanding of the influences on participation for individuals with SCI from the self-perceived perspective is required.

Objective: The aim of this study was to advance an understanding of how adults with SCI participate in daily life and their communities.

Methods: A grounded theory study of 19 adults with SCI was conducted. Participants engaged in individual in-depth interviews, and took photographs of aspects of their environment that promoted and restricted participation. Analysis consisted of an inductive process of constant comparison. A focus group with participants was held to discuss and contribute to the credibility of findings.

Results: The constructed grounded theory model is summarized as follows: *Negotiating the Body-Environment Interface* is a continuous process for those living with a SCI. Despite the relative stability of their changed body, they *Live in a Changed World*, one that is perceived differently after SCI. People use various strategies to interact within their environment, in order to engage in a *Process of Participation*. Intervening conditions are the environmental aspects that serve as barriers or facilitators to this process of participation.

Conclusion: Study findings lend support to the need for a self-perceived definition of participation. The theory constructed in this study can be used to target interventions intended to improve the participation experiences of individuals with SCI.

Approximately 85,000 Canadians are living with a spinal cord injury (SCI), with over 4000 new injuries reported each year (Rick Hansen Institute and Urban Futures, 2010). The effects of SCI are life-changing; the term “biographical disruption” (Bury, 1982) has been used to describe how a SCI can affect an individual’s life course and self-identity (Hammell, 2007). Over the last decade, participation has been identified as the foremost outcome of the rehabilitation process for health care professionals working with individuals with disabilities (Cardol, De Jong, & Ward, 2002; Chan & Chan, 2007; Coster & Khetani, 2008; Noreau, Fougereyrollas, & Boschen, 2005; Perenboom & Chorus, 2003). Participation is not a new construct; in the rehabilitation literature it has been used synonymously with various other terms, including social adjustment, independent living, social functioning, engagement, and community integration (Cicerone, 2004; Dijkers, Whiteneck, & El-Jaroudi, 2000; Hammel, Jones, Gossett, & Morgan, 2006; Rochette, Korner-Bitensky, & Levasseur, 2006).

Participation can be defined in objective (society-perceived) or subjective (self-perceived) terms (Noreau et al., 2005). Society-perceived participation is based on societal imposed norms of what is expected of individuals of a particular age and culture (Cardol et al., 2002). The International Classification of Functioning, Disability, and Health (ICF) defines participation as “involvement in a life situation” (World Health Organization, 2001) and distinguishes objective involvement as the object of interest. Although widely accepted as a classification system in health care, the ICF has received criticism for its universal classification of individuals with disabilities that perpetuates professional dominance (Hammell, 2006) and an assessment of the individual and

environment that fails to recognize the transactive nature of this relationship (Hammel et al., 2008).

In contrast, the self-perceived perspective defines participation in terms of the belonging and connectivity individuals have with their environment (Hammel et al., 2006). From this perspective, the individual is the only one who can truly define and understand participation (Perenboom & Chrous, 2003). Participation is viewed as a process that continues through life rather than as solely an outcome of rehabilitation (Carpenter, Forwell, Jongbloed, & Backman, 2007; Hammel et al., 2006), and consistent with the social model of disability, focuses on the lived experience of individuals participating in their lives and communities (Harris, 2007). Studies among individuals with SCI have predominately used society-perceived perspectives to explore participation. However, there are discrepancies between studies in the relationship between participation and life satisfaction of adults with SCI, with some identifying a positive relationship (Anderson, Vogel, Betz, & Willis, 2004; Lund, Nordlund, Bernspång, & Lexell, 2007), and others a limited relationship (Whiteneck et al., 2004). Some studies of adults with SCI have identified that participation is enabled as environmental barriers are removed (Lysack, Komanecky, Kavel, Cross, & Neufeld, 2007; Ward, Mitchell, & Price, 2007), while others have found that environmental barriers had a limited influence on participation in this population (Whiteneck et al., 2004). Differences in these studies may in part be attributed to the differing conceptualization and measurement of participation.

In one recent study of self-perceived participation of men with SCI during the transition from hospital to home (Van de Velde, Bracke, Van Hove, Josephsson, & Vanderstraeten, 2010), participation was depicted as a set of values that included occupying time, achievement, inclusion, and having a sense of control through activity. These authors stressed the need to gain understanding from individuals with SCI with a greater range of diversity, including longer time in the community and augmenting findings with additional research methods beyond individual interviews.

Thus, although there is a developing understanding of participation among adults with SCI, there is a pressing need to develop a more comprehensive theoretical rendering. Studies based solely on society-perceived perspectives cannot fully take into account the contextual nuances and perceived meaning of participation (Lysack et al., 2007). Constructing an understanding of participation that privileges the perspectives of those who hold the lived experience of SCI adds to the developing understanding of the construct of participation (Hammel et al, 2008; Van de Velde et al., 2010; Ward et al., 2007). Thus, the purpose of this study was to advance an understanding of how adults with SCI participate in their daily life and their communities, in order to promote opportunity for participation.

### **Theoretical foundation**

This study was theoretically guided by symbolic interactionism, with the assumption that humans act in a way consistent with the meaning they ascribe to a situation (Berg, 2001). Through naturalistic inquiry of inter-subjective experience and

inductive analysis researchers can come to understand this meaning conveyed to them through language and communication (Berg, 2001; Dietz, 1994; Prus, 1996).

Constructivist grounded theory (Charmaz, 2006) was used as a means to understand social processes and structures and to develop theory related to participation experiences of adults with SCI, based on an assumption that the researcher and the participant co-construct the data and its meaning. Overall, an interpretive and theoretical understanding of the data was sought, rather than a conclusive explanatory understanding (Charmaz).

### **Participants**

Participants in this study were adults with a SCI residing in one Canadian province. Participants were recruited by advertising within a wide range of organizations providing services to individuals with SCI. Initial sampling strategies were used to ensure participants varied with respect to gender, age, rural versus urban-dwelling, socio-economic status, and length of time since injury. Subsequent sampling focused on inviting participants whose data would assist in developing and clarifying relationships between categories, and identifying processes in existence (Charmaz, 2006; Coyne, 1997). An a priori sample size was not developed; rather saturation of category properties achieved through constant comparative analysis dictated the final sample size. In total, 19 adults with SCI were recruited. Table 1 provides participant demographics.

The study was approved by the University of Manitoba Health Research Ethics Board and all participants provided informed consent prior to data collection. As the data collection occurred over a prolonged period (up to 12 months), a process of reaffirming

consent was used to ensure participants' interest in continuing. As a result, some participants chose not to continue the study after completing the first or second interview (n=19 completed the first interview; n=15 completed the second interview; n=13 contributed to verification of the findings). To maintain anonymity of participants, pseudonyms were assigned.

### **Data Collection**

This study included three primary data collection methods. First, in-depth intensive individual interviews were held with each participant to gain an understanding of each individual's experience of disability, and to gather rich and detailed descriptions of the meaning of, and experience of, participation. Although the initial semi-structured question route was developed based on explicating the role of assistive technology (AT) in participation, through analysis, it became clear that AT was only one of several strategies that participants used to engage in a process of participation. Thus, the question route was refined as the study progressed to follow developing theoretical categories that emerged. Each interview was digitally recorded and transcribed in full, at which point personal identifiers were removed and pseudonyms assigned. At the conclusion of each interview, the interviewer recorded field notes to describe the context of the interview, personal perceptions of the interview, and a description of the communication process.

Photovoice was used to capture participants' insider perspective on the meaning of, and influences on, participation. Photovoice is a participatory and empowerment focused method whereby participants inform researchers of community assets and

deficits using self-selected photographs (Strack, Magill, & McDonagh, 2004; Wang & Burris, 1997). Following the first interview, information on the photovoice was discussed. Camera accessibility was addressed for those participants who required adaptations. Participants were asked to photograph relevant individual, family and community life experiences that illustrate the meaning and experience of social and community participation. Between the first and second interviews, participants were asked to select 10-15 photos that best represented their participation experiences.

The second interview was focused using the SHOWED method (Dahan et al., 2007), a technique that encourages discussion on the meaning of the photos to the participants. The photos and emergent ideas around participation were analysed and presented back to participants in one of two focus groups (n=8) or through a photo book (n=5). Using a semi-structured interview guide, participants discussed the photos and engaged in critical dialogue about their participation experiences. Participants received an honorarium for each interview completed, and kept the digital camera at the conclusion of the study. The first author (JR) conducted the interviews, camera assessments, and focus groups.

### **Data Analysis**

Data analysis focused on the meanings, intentions, and actions of the participants using a process of constant comparative analysis (Charmaz, 2006). Each interview transcript was subject to repeated readings to gain a sense of the whole, and with an intent to code the processes occurring. Using selective coding, the most significant codes



were chosen in a process of beginning to organize the data. Through a process of memo-writing, some codes were raised to the level of categories, and used to label generic processes. Finally, categories were examined for their developing relationships between categories (Charmaz, 2001; 2006).

Rigour in the study was addressed in several ways. Participants had a prolonged engagement in the topic area, promoting on-going reflection and development of the findings. The use of multiple data collection methods (interviews, self-selected photographs, and focus groups) and sources (participants) contributed to triangulation of findings (Patton, 2002). In the focus groups, participants confirmed that the findings reflected their participation experiences. An audit trail was developed throughout the data analysis process, and the first author reviewed emergent interpretations with peers with expertise either in qualitative inquiry or working with individuals with SCI (Law & MacDermid, 2008). Reflexivity was maintained through on-going documentation in a research log and juxtaposing this reflection against the data in the analysis process (Cocks, 2006).

### **Findings**

Overall, the categories that emerged were found to hold true regardless of the age, gender, or length of time since injury of participants. However, some differences were evident between participants who had sustained their injury in childhood or as an adult, for example as described in the category *Living in a Changed World*. The variations

within how the categories were expressed provided dimension and nuance to each of the constructed categories.

*Living in a Changed World* was the core phenomenon, characterized as the time after SCI when the person has returned home from hospital. Although their world does not physically change following a SCI, their interaction within that world does. The term “whirlwind” was used by a participant to describe the time after SCI when this changed world was first experienced: “Yeah, um, to go from, you know, pretty much complete freedom in life, being able to do whatever you wanted...to having to, if you want to do something there’s so many more factors you have to take into account, you know. Ah, can I even get to the place I want to go?” What was previously taken for granted now becomes a barrier to engagement in community life. Kevin described this as follows: “You don’t realize how inaccessible the world is until you are in one of these” (referring to his wheelchair).

Beyond the perception of a changed environment, involvement in previously valued activities was altered, so much so that many did not return to those activities. For instance, Harrison said:

I haven’t participated in, like things I used to do before. Like I don’t really, I guess with the boxing for example. Like I’ve gone a few times just to watch fights and stuff like that, but I haven’t really done too much more other than that...I guess I don’t, I don’t know, don’t really like going there too much. It’s just too different, I guess.

Although some barriers might be surmountable, the modifications required made engaging in the activity unacceptable, as David stated: “I’ve tried every which way to try to get back to golf. I was an avid golfer and I’ve tried different chairs and different ways to hold them it just wasn’t there.” If a person is unable to accept that performance of the activity can be experienced in a modified way, they may reject engagement in that activity (Corbin & Strauss, 1991).

This experience was different, however, for those who grew up with a SCI, where the introduction of AT often created a change in world perception. As a child, Vern was dependent for mobility and lived in an institutional setting. He describes first acquiring a power wheelchair: “But I get this electric wheelchair, suddenly I can go down the hallway and I can visit anybody and I can, I can go from one room to the other.” Although facing the same environmental barriers as those who sustained an injury later in life, they had created their world around them through choice of accessible living situations, selection of career, and engagement in leisure activities.

### **Negotiating the body/environment interface**

The core psychosocial process constructed was in response to the question: “How do individuals with SCI create opportunities for participation?” It was discovered that participants engaged in a process of negotiating the body (physical, cognitive, emotional) and environment (social, architectural, physical) interface to seek and create opportunities for participation. Participants engaged in this process to find “new ways of performing

through the use of other people, devices, or through the substitution of working body parts for failed ones” (Corbin & Strauss, 1987, p.267).

Part of the experience of SCI related to bodily changes. Although a few participants expressed concern about pressure sore development and pain, it was not predominant. Instead of limiting participation, participants described modifying activities and making choices based on these physiological issues. For example, some reported engaging in only one extra activity beyond their daily routine per day due to fatigue, as was the case with Tom, who described how his daily routine, travel arrangements, and selection of AT are highly driven by his desire to prevent the development of pressure ulcers. In contrast, Boschen, Tonack, & Gargaro (2003) reported that chronic pain was an important limiter in terms of daily activities and community integration for individuals with SCI.

Individual ascription on cause of disability related to the individual’s biological or social interpretation of disability. Most participants were on a continuum, anchored at one end with a belief system that society disables individuals through environmental barriers and exclusionary practices (Barnes, 2004; Oliver, 1998), and at the other end, attributing one’s own physical impairments as the barrier to participation. This belief system resulted in different ways of negotiating the body-environment interface, and Wilson and Josef represented two extremes of this viewpoint. Wilson was involved in advocacy at a policy level, sharing a picture of his participation in a political meeting around an accessibility issue, and describing it as follows: “So this photo to me in a sense means

change can be done.” On the other extreme, Josef took an individualized approach to addressing the barriers that existed, stating: “As I said before I also like the idea of trying to adapt yourself, so I, I wanted more training with going onto and off of curbs.”

Although participants acknowledged the environmental barriers, they tended to address them in individual ways, often using technological or human resources. For example, Tom bought a new wheelchair: “And in most places, well there’s a lot of them I can’t get into cause they just have 2 or 3 inch steps and this chair will...(go up that step)...it states 4 inches.” Rarely did they try to alter the environment, those with a lifetime experience of SCI often becoming disillusioned with their personal lack of impact. The variation in perspective was also identified in a study of 1356 individuals with cervical SCI in France, in which only one-third of participants felt that most environmental difficulties could be addressed through social or political action (Ville, Crost, & Ravaud, 2003).

One aspect of *Negotiating the body-environment interface* was recognition of access issues. Considering how one would overcome barriers prior to going out became important, as Tom relayed: “I think once you land up in a chair, you think about it a lot more. What ah...where can I go? How can I get in there? Will I take someone to help me?” Furthermore, considering whether a place would be accessible meant sometimes choosing not to go somewhere that is inaccessible, implementing strategies to enable access, or limiting ones’ choice of activities. Despite international legislation and increased societal awareness of the need for accessible public spaces, many inaccessible

public buildings and facilities continue to exist (Carpenter et al., 2007; Chaves et al., 2004; Meyers, Anderson, Miller, Shipp, & Hoenig, 2002; van de Ven, Post, de Witte, & van den Heuvel, 2008); for participants in the current study these inaccessible public spaces now required consideration.

Societal attitudes, which prior to SCI were often unrecognized by participants, became a new concern. Elinor described dealing with negative attitudes as a new wheelchair user:

The worst thing that I always remember is when I first got out of the hospital I was at (store)... And this woman came barreling out and almost banged into me. She just looked at me and she says “You people shouldn’t be in stores like this. All you do is cause troubles for people like me.”

Even family and established friendships were not immune from the expression of hurtful attitudes. Fynn took a picture of a friend that he had recently re-established a friendship with, commenting: “The last time I seen him I was in the hospital bed fifteen years ago...it took a long time for him to accept my being in the chair.”

### **Engaging in a process of participation**

Participants described participation as an experience, explaining what it meant “to participate” rather than identifying specific activities or roles. Participation was viewed as the consequence of negotiating the body-environment interface and was described in four ways: inclusion, opportunity for reciprocity, accomplishment, and autonomy. Although

these experiences were lived out in the context of a meaningful activity or relationship, the activity or relationship was a means, rather than an end, for achieving that experience.

Terms used to describe the sense of inclusion included: “feeling a part of something”, “feeling welcome”, and a “sense of belonging”, findings similar to those reported by Milner and Kelly (2009). A social setting was the venue for these feelings, and included the sense of meaningful involvement in activities. The experience of inclusion was contrasted with that of segregation, a feeling experienced by one participant when visiting a restaurant with higher tables that prevented him from sitting with friends. A second participation experience was labeled reciprocity. Reciprocity, or giving back, was accomplished through sharing ones’ life story, volunteer work, educating others, or coaching. Nancy described it this way: “it’s dealing with ways or possibly improving your community and enriching, not only your own life, but other people’s.” A third participation experience was a sense of accomplishment, best described by Wilson as “contributing effort towards something” and resulted in feelings of pride. Sports and leisure activities were important venues for this sense of accomplishment to be actualized. For example, David conveyed how his involvement in antique car restoration resulted in a feeling of accomplishment. The final participation experience expressed was autonomy. In particular, decisional autonomy (Reid, Angus, McKeever, & Miller, 2003) was described, as Marlene said: “to do what you want and where you want and when you want”, or as Vern called it “mental independence”. This included a sense of control over managing one’s own time and the opportunity to make one’s own decisions. Boschen et al. (2003) also highlighted the importance of autonomy,

where the perceived lack of choice and control that people with SCI experienced impacted social participation and quality of life.

### **Strategies**

Participants in this study engaged in four main strategies in order to *Negotiate the body-environment interface*: creating an accessible proximal environment; using AT and adaptations; advocating and educating; and gaining information and knowledge.

Development of personal space and an environment that was accessible was a strategy engaged in by all participants. When financially possible, many modified, built, or rented accessible homes. Wilson shared a photo, stating: “This is my apartment... which is universal design and level entry. This basically just shows how an apartment can be quite beautiful with also being accessible.” As noted in a cross-sectional study of individuals with SCI, “moving around inside your home” was generally not problematic; authors concluded that housing adaptations must be adequately meeting the needs of these individuals (Noreau & Fougereyrollas, 2000).

Assistive technology has been described as serving to “broaden the possibilities and opportunities of people with disabilities” (van de Ven, Post, de Witte, & van den Heuvel, 2005, p.322). Similarly, participants in the present study described AT as “freedom” and “a way to overcome barriers”. David shared a picture of his leg braces, and captioned it: “[The braces] just really kept me going for 29 years...without them I would be totally lost.” When not commercially available, participants developed new technologies to meet their needs, concurring with the findings of Wee and Paterson



(2009). For example, Vern took a picture of a device he developed with rehabilitation engineers:

So I have this hand warmer that I can carry around with me... You know I used to be able to go out at ten [degrees] above, now I go out at zero [degrees] above because I know my, I know my hands are not going to get so cold they can't move.

The importance of AT for leisure was emphasized; participants used adaptations to engage in sports such as sledge hockey, curling, fishing, biking, and sailing. The social value of leisure engagement was highlighted, and the adaptations supported participants' ability to engage in family-based activities. For those who owned their own van, the vehicle was viewed as essential for spontaneous community participation. Tom stated: "It's a world of difference having your own vehicle, just get up and go when you want to." Similar to the findings of other studies (Boschen et al., 2003; Ville et al., 2003; Wee & Paterson, 2009), having a vehicle allowed for independence and convenience that was not available through public transportation.

Participants engaged in a wide variety of outwardly-directed strategies (van de Ven et al., 2005) intended to influence others. Some took a conciliatory approach, others an assertive approach, whereas others found ways to serve as a resource, educating society around accessibility issues. Garrett described engaging with others to address accessibility barriers in this way: "so you need to do this, and I need to do this, so let's figure it out". Often, participants served as informal resources around their experience of

living with a SCI or accessibility issues. Others took an assertive approach to ensuring needs were met and rights were not violated. As Elinor commented: “I’ve learned over the years that if you don’t open your mouth, people stomp all over you, they don’t care.”

Persistence and energy were required when engaging in advocacy efforts, as summed up by Vern: “[you need to] put the ideas out there, you put them out there, and put them out there, and put them out there.” At times, participants chose not to advocate as they felt to do so would be futile, or they felt patronized; Jayna described one advocacy experience as “disheartening and demoralizing”, and Olivia reflected, “So many people with disabilities don’t complain...we’re worried about losing services.”

Other strategies were inwardly directed (van de Ven et al., 2005), focused on gathering information needed for decision-making. For example, learning whether or not a space was accessible was an important strategy. Oftentimes a person would be told that an environment was accessible only to find out that it was not; Marlene described how she “got burned once, didn’t bother getting burned again”. Most wanted to “see it for themselves” (Reed) and known inaccessible spaces were generally avoided.

### **Intervening conditions**

Intervening conditions were the social, physical, financial, and institutional resources of participants that could serve as either supports or barriers, to participation. Corbin and Strauss (1987) suggest that environmental changes that are supportive and enhance the ability of individuals with disabilities positively affect “body performance”

and reduce the “biographical work” required to reconcile the body-environment interface (p.279).

The importance of family was evident in the interviews and pictures participants took of their participation experiences, as Olivia stated: “Family is like the most important part in my life.” Besides providing emotional support, family and friends were an invaluable in providing the physical support to overcome accessibility barriers. Most described how friends “bumped” (lifted them up) stairs or curbs; such supports enabled access to inaccessible environments. Having these social resources available supported the ability to go wherever one desired, for instance, Nancy stated: “If you’ve got the right people around, anything is possible”. Similarly, a social network offering physical, social, and emotional support has been identified as valuable in multiple other studies (e.g., Boschen et al., 2003; Chan & Chan, 2007; Wee & Paterson, 2009). Health care supports were a part of many peoples’ lives, assisting with personal care and home management. The importance of finding a helpful person who also meshed in terms of personality was essential. Many relayed stories of challenging situations with health or home care staff; finding a good person was a “godsend” (Tom). For some, the local spinal cord injury support organization was identified as important, primarily in regard to a specific counselor who had been helpful to them in advising or assisting them with advocacy efforts.

Family and friends also created accessible entrances and spaces to their homes. This extended beyond close social relationships as, when a personal connection existed

(as a member of a church congregation or a customer in a regularly frequented store), temporary ramps were placed on stairs, or new ramps or widened doorways were installed during renovations. The importance of these modifications was stressed by Jayna, who described how lack of a ramp created more than just a physical barrier: “There was just no freedom ... I mean I can jump down the stairs myself if I wanted to but it’s the being able to come and go. To come and go as you wish.”

For those without private transportation, the importance of public transportation was stressed. Those who used disability-specific public transportation held strong views about this service. Participants relied on this service yet felt powerless to express concerns: “It puts a little bit of fear in me to say like if they're going to take [public disability transportation service] away from me, then what's going to happen to me? My independence goes down so much” (Olivia). Lack of appropriate transportation has been frequently identified as an environmental barrier for individuals with SCI (Carpenter et al., 2007; Lysack et al., 2007; Whiteneck et al., 2004).

For those who required custom AT modifications to ensure function and comfort, there was a close relationship with rehabilitation engineers; David referred to his orthotist as a “lifesaver” and that he would be “lost” without access to this person. However, funders were viewed as the gatekeepers to obtaining equipment and an adversarial relationship with funders was the norm. Fynn described “fighting tooth and nail” to receive a modified van, illustrating the challenge of obtaining equipment that one needed. Funders wielded perceived power in other ways; for example, when participants tried to

supplement their income to make purchases not prioritized by funders, they kept activities secretive for fear of repercussion. Funding policies often appeared unreasonable and lacked transparency, making it unclear how decisions were made and thus what information should be shared with funders. Despite not knowing the rules, there was a perception that people needed to “follow the rules”, or face ramifications.

Community access was a key facilitator of participation for participants.

Accessible environments supported people’s engagement in important and meaningful activities. Those with long-standing injuries commented on the improvements they had seen in accessibility over the years in terms of architectural accessibility and attitudes, with more awareness of the rights of people with disabilities. Garrett, who had travelled internationally, stated he felt “blessed to live in North America because you can go somewhere and kind of expect that you’ll probably get in.” However, photos also captured inaccessible public spaces. Accessibility was often limited by uneven sidewalks, poor parking options and perceived misuse of assigned handicapped parking stalls, and features of building entrances such as high curbs, stairs, and absent automatic door opener buttons. Additional barriers included washroom stalls that could not accommodate wheelchair users and narrow doorways, hallways, and aisles. For example, Jayna shared a picture of a school: “My son's school has three levels, and this is how everyone gets to the office, stairs. My son went to this school for seven years and I haven't seen his desk or classroom in the last four years.” *Pseudo-accessible* public spaces, spaces that had some aspects of accessibility yet remained inaccessible, were also frequently identified. For example, Vern identified a building with an automatic button door opener, but with a

two-inch ledge into the building, stating: “What good is the button, when you can’t get into the building anyway?”

Natural and climatic environment barriers have been frequently cited (Boschen et al., 2003; Hammell, 2007; Lysack et al., 2007; Reid et al., 2003; Wee & Paterson, 2009). Our study confirmed these findings. Public spaces such as parks and playgrounds were generally inaccessible, with ground surfacing identified as the most problematic feature. Sub-zero temperatures, snow, and ice, were an ongoing challenge. Some participants avoided or minimized outdoor activities, whereas others utilized strategies to address winter barriers, such as driving their wheelchairs on the road to avoid impassable sidewalks: “In the summer I’m a pedestrian and in the winter I’m a car” (Wilson).

Accessibility for participants referred to more than the physical environment, it involved “enabling dignified inclusion in services, activities, and relationships” (Semple, Blowes, Steggles & Baptiste, 2010, p.16). In general, society was viewed as kind and accommodating and most felt that if they asked for help it was provided. However, many reported negative interactions and some deemed assistance provided as *overly* helpful, particularly when unrequested or unsolicited, a finding also discussed by Wee and Paterson (2009). Tom described it this way: “Yeah, everybody wants to help somebody in a wheelchair. At least that’s what it seems to me.” Others believed that the public lack disability awareness, would not notice if assistance was needed, avoided interaction, made negative assumptions about the capacity of participants, or acted with a sense of entitlement, for example when they failed to give up priority bus seating. Most

participants relayed at least one incident when they were affected by someone's lack of consideration or hurtful comments. Jayna stated, "It only takes one bad apple but still they, they have the loudest voice" to describe how the negative comments would stand out in their mind. Negative interactions and societal responses strikingly similar to those of the present study's participants have been previously reported (Boschen et al, 2003; van de Ven et al., 2005; Wee & Paterson, 2009). It is apparent from study results that attitudinal barriers continue to exist.

### **Discussion**

Using symbolic interaction as a framework, we were able to understand both the micro and macro-level interactions between person and environment as it pertained to his/her experience of participation. Participants' self-selected photos provided the insider perspective of their experiences, consistent with Brown (2010) who stressed that what is perceived as a barrier or support "varies across insiders because it is shaped not by the fact of disablement per se but by that fact filtered through the person's experiences, values, and beliefs" (p. S34). The interviews driven by the photos provided an enhanced understanding of how participation was perceived in the context of self-selected activities.

The grounded theory model constructed from the data (Figure 1) is summarized as follows: "Negotiating the body/environment interface" is a continuous process for those living with a SCI. Despite the relative stability of their changed body, they "Live in a changed world", one that is perceived differently after SCI. People use various strategies,

in order to engage in a “process of participation”. Various intervening conditions serve as barriers or facilitators of participation, related to the physical, social, and attitudinal environments. These conditions influence the persons’ ability to negotiate their body/environment interface and subsequently direct their selection of strategies.

The integral role of the environment in creating opportunities and barriers to participation was supported by the findings of this study, as has been reported by others (e.g., Noreau & Boschen, 2010; Van de ven et al., 2005). Similar to other models, the environment was identified as influential and experienced in a transactive manner to promote opportunities and create challenges to participation of these participants (Fougeyrollas, Noreau, & Boschen, 2002; World Health Organization, 2001). However, in this study, inaccessibility did not prevent participants from engaging in a process of participation as participation was not defined by the activity in which one was or was not involved. rather they developed and used strategies to address these environments. Individuals in the current study actively interacted within their environment to develop a sense of identity, establish meaning, and engage in a process of participation. Engagement within personal and community environments was essential to negotiating the body-environment interface. As Corbin and Strauss (1987) stated it is:

through continued self and other validation of each successful performance – however altered, changed or flawed the performances may be – the ill [sic] person begins once more to achieve a sense of identity integration, a feeling of wholeness about identity (p.274).



Participants did not define participation by a type, or amount, of engagement in certain activities, rather they sought ways to satisfy their participation needs of accomplishment, autonomy, opportunity for reciprocity, and inclusion through the use of strategies they engaged in with support of, or in spite of, environmental factors. Describing participation as a set of values is consistent with the findings of recent qualitative studies on the self-perceived meaning of participation (Hammel et al., 2008; Van de Velde et al., 2010; van de Ven et al., 2005). Recognizing that the sociocultural position and context of an individual will influence social participation, roles and perceptions of an individual (Fougeyrollas et al., 2002), participants were in the situated context of being residents of a society where Western ideologies promoting independence, equality, self-determinism, and rational agency prevail (Iwama, Thomson, & Macdonald, 2009). Terms used to describe participation experiences, such as accomplishment and autonomy, were clearly aligned with a Western worldview. However, participants also described values of inclusion and reciprocity, values more in keeping with collectivist societies that regard social relationships, interdependence, and a sense of belonging as paramount (Hammell, Miller, Forwell, Forman, & Jacobson, 2009; Iwama et al., 2009).

### **Limitations**

Despite the fact that the findings did not demonstrate age or gender related differences between participants, the sample size was small and with a larger sample size, some of these differences may become evident. Future studies could examine self-perceived participation amongst a smaller age range, or amongst a specific gender to

better understand how these aspects might influence perspective. All participants were Caucasian and thus future studies should seek to gain insight into the perspectives of those with different ethnic backgrounds. The data was collected over a relatively short period, and thus does not represent participation experiences across the disability trajectory of these participants. By conducting longitudinal studies, knowledge of the process of participation for adults with SCI over time could be developed. We were aware of issues of reflexivity as the first author was the interviewer, conducted the primary data analysis, and is an occupational therapist researcher with an interest in modifying environments to promote occupational engagement. Discussion with the second author and peers, detailed probing with participants who held differing views than those of the interviewer, extensive field notes, and repeated review of transcripts prior to subsequent interviews were used as methods to address reflexivity.

### **Implications for practice**

As rehabilitation professionals working with individuals with SCI, and who seek to promote, facilitate, and enhance their participation, we need to know what it is we are working toward. Understanding participation as an experience given meaning through selected activities and roles will help in the crucial conversations service providers have with individuals who are living in a changed world. Working with individuals after SCI, rehabilitation professionals can assist people to develop the strategies identified as essential in this study. Furthermore, those working with individuals after SCI must continue to recognize the transactive nature of the individual and environment. As stated by Fougeyrollas et al. “the environment cannot be considered as an accessory or an added

piece of information that can be taken into account after the active process of rehabilitation is completed” (2002, p. 13).

There is a further responsibility on service providers to positively influence the intervening conditions at a societal level to ultimately create opportunity for participation. Advocating for improved community accessibility, promoting the development of appropriate and transparent policy, and educating society on the accessibility issues are essential roles for clinicians.

Dijkers reminds us that “(p)articipation is a key outcome of rehabilitation and of other medical and social service programs” (2010, p.S5), consequently substantial effort is currently being directed towards conceptualizing and measuring participation. However, constructing only society-perceived perceptions of participation is an “injustice to the values and goals of the person served’ (Brown et al., 2004, p.462). It is clear that the self-perceived aspect of participation should not be excluded from this discourse. With the rapidly growing body of literature on self-perceived participation, meta-synthesis of this information would be useful and timely (Dijkers).

Although several studies have identified barriers to, or explored influencing factors on, participation amongst individuals with SCI, most have used a lens of society-perceived participation. This grounded theory study sought to understand from people with SCI the process they engage in to facilitate participation, as defined by the participants. By elucidating the strategies used by individuals to engage in a process of participation, and highlighting the factors that promote and prevent participation, we

position ourselves to better support the full inclusion and participation of individuals with SCI, supporting efforts of working towards development of a more inclusive society.

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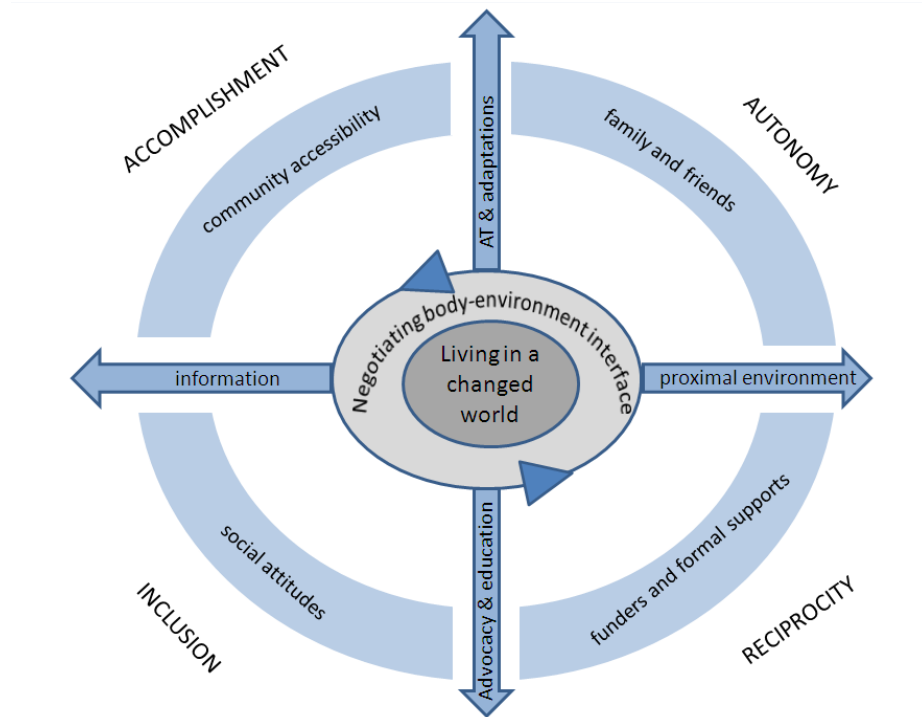
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**Table 1. Participant Demographics**

Gender	
Male	n=13
Female	n= 6
Age range (years)	
20-39	n=7
40-59	n=11
60 +	n=1
Nature of SCI	
Traumatic	n=15
Congenital/disease	n=4
Level/type of injury	
Tetraplegia	n=8
incomplete	n=4
Vocation	
Post-secondary student	n=4
Full-time parent	n=2
Full-time paid employment	n=3
Self-employed	n=3
Volunteer/community work	n=7
Living situation	

Owned home	n=11
Shared services apartment	n=4
Rented apartment	n=4
Social supports at home	
Lived with spouse or family	n=7
Lived alone	n=11

**Figure 1. Toward a Grounded Theory Model of Participation Amongst Adults with Spinal Cord Injuries**





## Chapter 6: Introduction to Chapter 7

Through the inductive nature of the research, it became apparent that assistive technology was one of four sets of strategies that individuals with SCI engaged in their participation experiences. The second manuscript, *The Intersection of Culture, Disability, and Assistive Technology*, examines what the literature says about how culture affects the meaning of assistive technology at an individual and societal level. This theoretical paper critically examines the role that culture plays in the assumptions made by assistive technology providers and challenges clinicians to suspend and question their own assumptions.

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## **Chapter 7: The intersection of culture, disability and assistive technology**

### **Abstract**

**Purpose:** Although the use of assistive technology (AT) is by an individual, it occurs within a much larger socio-cultural environment. The purpose of this article is to describe and analyze current knowledge about the intersection of culture and disability in the context of the AT user.

**Methods:** Literature review of theoretical and empirical study papers that discuss cultural aspects related to AT use or provision.

**Results:** Understanding how an individual's culturally defined identity is shaped as an AT user, and the meaning the AT holds to that person and family, is essential to providing culturally appropriate AT services. AT providers also belong to a culture framed by their professional experiences; needed are ways of addressing ethnocentricity within culturally diverse practice settings. Some AT users may identify with a disability culture, a culture formed by a shared set of beliefs, values, and behaviors around the construct of disability.

**Conclusion:** This review reveals there is a paucity of knowledge about the intersection of AT and culture, and that this intersection requires further research. Embarking on this investigation is mandatory if we seek to meet the needs of the culturally diverse individuals who use AT.

**Keywords:** Culture, assistive technology, culturally relevant service, social constructionism, disability

## **Introduction**

Identity, culture and technology are necessarily intertwined (Seymour, 2005). For an individual with a disability who is an assistive technology (AT) user, this relationship becomes even closer due to the visibility of AT and, in some instances, the lack of choice the individual has around using the AT. In the field of AT, understanding the interactive nature of the person, environment and AT is a well-accepted framework for considering the role of the technology in the life of a person with a disability (Cook & Hussey, 2002; Scherer & Craddock, 2002). To date, most of the discussion on the environment has concentrated on the physical and social aspects and how they influence an individual's use of a device. However, the cultural environment deserves equal consideration, as it will inevitably shape perceived meaning and subsequent use of a particular device.

The purpose of this article is to examine how culture and disability have been approached in the literature, with particular focus on the AT user. At the intersection of these two constructs, and in the context of AT provision and use, cultural influences on AT can be considered in a variety of ways. Individuals who use AT and who identify with a minority or ethnic group may hold differing viewpoints on the meaning of disability, and the value of AT, than those in mainstream society. At an individual and family level, understanding how AT shapes an individual's culturally defined identity, and the meaning that the AT holds to that person and family, is a key aspect in providing culturally appropriate AT services. AT providers also belong to a culture framed by their educational and professional experiences; the danger of taking on an ethnocentric

perspective may result in their cultural viewpoints conflicting with their clients, leaving the provider wondering why a client does not want to use a particular AT. Within Western society, some AT users may identify with the concept of a disability culture; a culture that is not ethnically formed but one formed by a shared set of beliefs, values, and behaviours around the construct of disability (Tower, 2003). In this article, each of the aforementioned aspects of culture and disability are explored in the context of the AT user.

To explore the intersection of culture, disability and AT, keyword searches in Scopus, CINAHL, PubMed and Google Scholar were conducted. Literature published in the last decade, written in English, and that discussed cultural aspects related to AT use or provision was included. Theoretical and empirical research papers were sought. Additional foundational sources on culture and disability were identified to provide background and contextual information.

### **The meaning of culture and disability**

There are numerous definitions of culture in the literature. Traditional definitions are often synonymous with race or ethnicity, however, in current literature culture is said to “transcend individual embodiments of race and ethnicity” (Iwama, Thompson, & Macdonald, 2009, p.1126). Definitions of culture tend to take one of two forms: a materialist view where culture is defined by the behaviour and possessions of a group of people, or an ideational perspective where culture is related to a set of beliefs and values held by a group (Armstrong & Fitzgerald, 1996). Culture and disability studies tend to

focus on the ideational perspective (Armstrong & Fitzgerald), and therefore this perspective predominates in this article.

Thus, culture refers to the beliefs, values, meanings and actions that shape the lives of a collective of people, influencing the ways people think, live and act (Hammell, 2006; Iwama, 2005). These beliefs, values, and ways of understanding are socially constructed and specific to the culture in which they are found (Burr, 2003). The norms of a group or community are often unspoken and unquestioned (Hammell, 2006), result in the development of accepted rules of conduct as a member of that collective (Hetzroni & Harris, 1996) and are sustained by the social processes and interactions among group members (Burr, 2003; Tower, 2003). Furthermore, culture can be considered a dynamic process, formed by a “complex interplay of meanings that represents and shapes the individual and collective lives of people” (Iwama, 2005, p.216).

The intersection of culture and disability is complex as, on their own, culture and disability are each shaped by socially and individually defined values and beliefs (Brown, 1997; 2002). As with the definition of culture, disability is also defined in different ways; the meaning of disability varies greatly throughout the world and in different cultures (Bickenbach, 2009). Even within Western society, disability does not have an agreed upon definition but is based upon the paradigm adopted. For example, the International Classification of Functioning, Disability and Health adopts a biopsychosocial approach and proposes that disability is a negative state when an impairment, activity limitation or participation restriction exist, preventing execution of a specific task or action (World

Health Organization, 2001). Conversely, from a social model of disability perspective, disability resides outside of an individual and is a result of oppressive societal practices and environments that create disabling conditions (Barnes, 2003; Oliver, 1997). The difference in the source of disability (individual and society or society alone) inherent in these two models illustrates how diverse thinking about the concept of disability can lead to diverse ways of addressing issues related to disability.

### **Disability in the context of culture**

One method of understanding disability is in terms of the cultural patterns of meaning, values and purposes of social life within a particular context (Whyte & Ingstad, 1995). Social constructionism refers to the belief that truth and knowledge are socially constructed and relative to the context in which that knowledge is developed (Patton, 2002). People will develop and share knowledge about a phenomenon such as disability given their historical and cultural specificity; that understanding of disability will vary according to group norms, beliefs and values (Burr, 2003). Understanding a collective's belief system regarding normality, power, capacity, social existence, and relevance of the body provides insight into the meaning of disability within a cultural context (Whyte & Ingstad). Gaining an appreciation of the cultural groups that a person identifies with, and the set of values and beliefs that a person ascribes to, may provide some insight into his or her understanding of disability and ultimately how that person and family choose to address disability related issues. Asking several fundamental questions around the meaning of disability is a starting point in gaining this understanding for AT providers working with clients who hold diverse worldviews.

First, Armstrong and Fitzgerald (1996) suggest that there is a need to examine how disability is defined within a cultural group. They state that definitions will likely be both etic (based on culture-general ideas about disability) and emic (culture-specific knowledge about disability). Examples of etic definitions include the definition developed by the World Health Organization (2001; Ustun, Chatterji, Bickenbach, Trotter II, & Saxena, 2001), and the definition of disability used in the Americans with Disabilities Act. Emic definitions vary widely and are contextually specific. In addition, the word disability does not exist in some cultures but instead becomes subsumed by a term that refers to misfortune and thus those considered disabled might include those who were childless, without land, ill or widowed (Armstrong & Fitzgerald).

Second, to understand the meaning of disability held by the AT user, there is a need to understand the accepted explanation for disability (Armstrong & Fitzgerald, 1996). Explanations often take on a mix of interpretations amongst cultures, but can be grouped as originating at the individual, natural, social or supernatural world level. For example, the biomedical model explanation of disability lies at the individual level, while those with a social world level belief may understand disability to be the result of wronging another within ones' community. Others may hold a fatalistic perception of disability with a belief that the disability is a punishment for sin (Parette, 1999) or that disability is a matter of fate and thus nothing should be done to help the person. Armstrong and Fitzgerald (1996) claim that most cultural explanations focus on social or supernatural explanations of disability.

Next, cultural responses to disability need considering (Armstrong & Fitzgerald, 1996). On the basis of the socially constructed and understood meaning of disability by a group of people, social action believed appropriate to that meaning will be enacted (Burr, 2003). The cultural response taken will be closely related to the accepted explanation of disability, and thus is a crucial aspect of understanding the cultural response to AT. If the explanation of disability is located at the individual level, the cultural response will be an “expectation of self-help”: the individual is responsible as an autonomous being to deal with his or her disability (Armstrong & Fitzgerald, p.266). If the explanation lies in the social world, the disability may be viewed as shameful and the response may be to avoid the social world and maintain privacy (Armstrong & Fitzgerald; Parette, 1999). Finally, if the explanation is held at the supernatural level, the response depends on whether it is seen as fate and requires acceptance, or whether there is a need to restore balance within the supernatural world (Armstrong & Fitzgerald).

The cultural meaning and interpretation of disability will influence the coping and intervention strategies selected by the individual and family, and thus their willingness or interest in accessing health care support (Harry et al., 1995; Chiang & Hadadian, 2007). The meaning and use of disability supports (such as AT and rehabilitation) are generally formed by the cultural explanation of disability and the existing systems of support for the person with a disability (Armstrong & Fitzgerald, 1996). When formal structures and systems of disability services are used, they serve to draw more attention to people with disabilities. This emphasis may be unwanted by those who seek to keep disability a private family matter.



Finally, the social consequences of disability also exhibit cultural variation. Whether or not a particular attribute is valued in a particular society will vary greatly and determines the social consequence of a particular disability (Armstrong & Fitzgerald, 1996). Deal (2003) contends that a hierarchy of preference related to type of disability exists among non-disabled people in Western society, with fewer stigmas attached to those who come closest to socially constructed norms. In a 13 country cross-cultural validation study of the International Classification of Impairment, Disability and Handicap-2, individuals with mental health conditions (and particularly those with alcohol or drug-related conditions) were viewed with more stigma than those with physical disabilities; the former also elicited stronger negative public reactions (Roon, Rehm, Trotter II, Paglia, & Ustun, 2001). Furthermore, study participants suggested that those with mental health conditions were less deserving of assistance or health services than those with physical disabilities.

Disabilities that limit independence and productive work are viewed as a threat to personhood by Western standards, where values include equality and independence (Whyte & Ingstad, 1995). In other cultures, disabilities that limit one's ability to contribute to social relationships among interdependent families and communities may be of greater threat. Conversely, some disabilities may be highly valued by a community; for example in some cultures those with severe epilepsy are revered as holding special qualities reserved for shaman or other spiritual leaders (Fadiman, 1997).

It is helpful to examine how these questions about meaning and response to disability can be applied to broaden an AT providers understanding of culture and disability. For instance, Chiang and Hadadian (2007) described challenges that first generation Chinese-American families face when they have a child with a disability. These authors state that the term for disability in Chinese translates to mean ‘with obstacle’ or ‘useless’. When a child is born with a disability, it is evidence of bad karma from the past. The mother generally takes the blame for having borne the child with a disability and the family perceives that it is shameful to have this child. The response then may be for the mother to attempt to deal with all of the child’s issues on her own, avoid seeking help and limit social interactions.

However, it is imperative that AT providers working within a multicultural context recognize the risk of adopting the perspective that there are universal and consistent belief systems amongst culturally similar groups, as this view can serve to perpetuate stereotypes (Harry et al., 1995). Awareness and understanding of belief systems, or ways of knowing, is only partial knowledge (Harry, Rueda, & Kalyanpur, 1999), and seeking answers to the questions raised by Armstrong and Fitzgerald (1996) help one to gain that cursory knowledge. There are a range of cultural norms and heterogeneous values within groups, individuals vary in the level in that they identify with groups, and many individuals identify with more than one cultural group (Barnartt, 1996; Phinney, 1996). In working with culturally diverse individuals, there is a need to gain an understanding of, and respect for, the complex process of how individuals and families shape, interpret and express their cultural values and norms.

Consistent with a social constructionism perspective of culture, there is a further obligation to locate an understanding of meaning and response to disability in the socio-economic and historical circumstances that have been influential on groups of people, their experiences and their opportunities (Browne, 2009; Burr, 2003). For instance, Gerlach (2008) explored family norms and child rearing practices from the perspective of First Nations families of children with developmental disabilities in the Lil'wat Nation in British Columbia, Canada. In this study, the definition and meaning of disability revolved around specific causation beliefs about why their child had a particular condition, with some (but not all) holding fatalistic beliefs about causation. The response to disability in this study was to include the children within a 'circle of caring' and within the informants' support networks that extended to include the community. Participants countered suspicion about Western medicine using traditional healing practices such as smudging, and maintaining a close connection with the natural environment where natural objects were believed to carry healing powers. In this study, it was important to recognize the devastating impact of the residential school system on culture and identity as a key element in understanding the oppression and loss of identity experienced by First Nations people. Participants identified that, because of the loss of affection experienced by the older generation, they were committed to making a better life for their children.

Similarly, in the book *The Spirit Catches You and You Fall Down* (Fadiman, 1997), a Hmong family expresses conflicting views on how to treat their young daughter with severe epilepsy. However, these differences needed to be situated in the cultural context of the family, as well as in the context of the war in Laos and the loss of culture

experienced when the Hmong people sought refuge status in the United States. It is clear from the examples that the cultural meaning and response to disability cannot be isolated from the historical and political context that has shaped the experiences of a group of people.

### **Intersection between culture and identity for the AT user**

AT are considered an interface between the individual and their environment, elicit a behavioral response from others and are specific to the culture and society where they are found and used (Breines & Pellerito, 2003). Culture relates to ones' social construction of self within his or her environment (Iwama et al., 2009); accordingly, socio-cultural factors have been highlighted as influencing the meaning ascribed to AT (Pape, Kim, & Weiner, 2002).

Issues of identity have been suggested to play an important role in determining whether one decides to use the AT and in what context (Hocking, 1999); identity is shaped by socio-cultural factors that subsequently affect the AT user. People assign a symbolic value to AT based on socio-cultural norms; for example, it may be a symbol of improvement or decline, a tool of competence and capacity, or may serve to stigmatize or marginalize. How an individual perceives the AT to intersect with identity may take various forms (Kinavey, 2006): it may be integrated into their sense of self and serve as an extension of their body, or alternatively, it may serve as a symbol that sets them apart from others (Gooberman-Hill & Ebrahim, 2007; Skär, 2003; Toombs, 1995).

Cultural norms, and the consequential impact of AT on identity, may affect whether one chooses to use a device or not. Individuals and/or their families negotiate the socio-cultural meaning of an AT and influence on identity, and use that interpretation to decide whether to use AT and in what setting (Seymour, 2005). Cultural factors may be the primary influence on differences seen in AT usage patterns and attitudes towards AT amongst diverse individuals (Kaye, Yeager, & Reed, 2008; Ried et al., 1995). When an AT does not fit with ones' internalized view of self in terms of point in life cycle, social norms or cultural heritage, it may not be used (Pape et al., 2002). When AT does not promote a positive self-identity or hold an acceptable socio-cultural meaning, individuals may choose not to use one, choose to use a more socially accepted AT device (Goberman-Hill & Ebrahim, 2007) or use specific strategies to obscure AT use such as concealing it (Kent & Smith, 2006). It is important to recognize that most AT users exist within a multicultural context. He or she may be a member of a cultural group that holds certain attitudes and beliefs towards AT, while simultaneously belonging to the larger societal culture that perceives AT in a different way (Hetzroni & Harris, 1996). There may be considerable internal conflict when the AT user must reconcile meanings assigned to AT that are inconsistent and incongruent.

### **Cultural perspectives on AT use**

Constructions of disability intersect with gender, socio-economic status, education, acculturation, sexual identity and social class and thus culture and disability are difficult to consider in isolation (Harry et al., 1995; Parnes et al., 2009). In the AT literature, some attempt has been made to examine the intersection of disability and

culture in terms of the impact on AT use, and thus a brief summary of the findings will be shared. However, it is important to note that this literature has been limited to cross-sectional studies that have attempted to identify the unique influence of race on AT use, rather than employing a broader view of culture. As few people exist within a singular, homogenous culture (Hammell, 2009), these findings are limited. In one study of older adults who identified themselves as either Hispanic, non-Hispanic white or African-American, Carrasquillo et al. (2000) determined that African-American older adults were more likely to report using AT devices than non-Hispanic whites when accounting for age, gender and education. In contrast, Kaye et al. (2008) and Tomita et al. (1997) identified that non-Hispanic whites owned and used high technology AT devices more than African Americans and Latino individuals. In another study, researchers concluded that “whites are more likely to use devices that involve home modification and blacks are more likely to use more portable devices” (Rubin & White-Means, 2001, p.934).

Thus, these four studies identified conflicting results in terms of racial influences on AT use. In most cases, differences were further interpreted in the context of other variables, such as level of education (Kaye et al., 2008), health and social status (Tomita et al., 1997) and access to information services (Rubin & White-Means, 2001). It is likely that any differences found in these studies were more attributable to social factors than any inherent cultural or racial preferences for AT use.

### **Cultural perspectives on AT meaning**

Overall, AT providers believe that AT is needed and wanted by those who they perceive could benefit from it (Parette, 1999). For example, Kaye et al. (2008) suggest that individuals who do not fully exploit the advantages of AT may be disadvantaged in their ability to participate within their social and community structures. The cultural reference point of service providers is generally that of mainstream culture; societal value systems will further influence AT policy, funding and service delivery (Ustun et al., 2001; Whiteford & Wilcock, 2000). However, social constructionism reminds us that a critical stance needs to be taken toward the assertion that AT is positive and wanted, challenging the taken-for-granted assumptions held by AT providers (Burr, 2003).

Current AT theory and practice is based on Western philosophies and ideologies that favour autonomy, independence, and self-determinism (Iwama et al., 2005; Iwama, 2009). In rehabilitation theories, Iwama et al. (2009) observe that wellbeing is defined as the extent of control one has over ones' circumstances and environment, the self and environment are discrete and dependency is "an undesirable state" (p. 1127). However, adoption of these perspectives is not universal among those who construct their lives and realities with differing worldviews. AT service providers, researchers and writers also belong to a culture of their own. The fact is that the majority of this group are university-educated, middleclass and do not consider themselves disabled (Hetzroni & Harris, 1996). As individuals and as a collective, they hold power and the ability to perpetuate dominant cultural views on disability, (assistive) technology, and purpose. Publication and propagation of the body of academic and professional literature is one way to share

their views. In this literature, AT proposes to hold many purposes. Over the last decade, writers have described AT as a means for individuals with disabilities to improve functional performance (Cook & Hussey, 2002; Isabelle et al., 2002; Johnson, Dudgeon, Kuehn, & Walker, 2007; Judge, 2002; Ripat, 2006), gain greater control or mastery over their environment (Parette & Brotherson, 2004), promote individual empowerment (Hutzler, Fliess, Chacham, & Van den Auweele, 2002), foster positive psychological well-being (Craddock, 2006; Jutai & Day, 2002), provide a means to circumvent environmental barriers to activity participation (Pape et al., 2002), reduce physical demands on caregivers (Benedict, Lee, Marrujo, & Farel, 1999; Ostensjo, Carlberg, & Vollestad, 2005), provide the possibility of achieving a better life (McMillen & Soderberg, 2002) and increase societal participation (Campbell, Milbourne, & Wilcox, 2008; Copley & Ziviani, 2004; Jirikowic, Rickerson, & Burgstahler, 2003). The challenge is to remember that these values are not universally shared but are culturally specific to the Western (or minority) world (Hammell, 2009), and that each proposed purpose and benefit needs to be examined with a cultural lens as to whether or not it is relevant to the individual and family (Parette & Brotherson, 2004).

The view that one might be able to improve function and task performance using AT may not be as important to some. For example, within cultures where children learn through observation, with an expectation to engage in performing an activity only “if and when they are able” (Gerlach, 2008, p.23), AT may not be meaningful. The concept of valuing productivity is culturally specific, and some do not identify productive work as an indicator of a persons’ worth (Harry et al., 1999). Some people may not consider AT



intended to enhance productivity, such as software to increase the speed of typing, as valuable or necessary.

Values related to gaining mastery, control, independence, and autonomy are generally considered hallmarks of individualist societies (Iwama, 2003; Iwama et al., 2009). In contrast, members of collectivist societies are more likely to value social relationships, community, interdependence and a sense of belonging (Iwama et al.; Lomay & Hinkebein, 2006; Hammell, 2009). Accordingly, for members of collectivist societies, AT that promotes independence may not be highly valued (Parette, Huer, & Hourcade, 2003). Touting AT as a means of promoting independence may be counter-productive to an individual who considers him or herself an integrated and inseparable part of the environment. For individuals who hold a natural world understanding of disability, it may be more important to determine whether the AT assists the individual to live in harmony with, rather than control, their environment (Iwama et al.).

The claim that AT can promote psychological well-being needs situating in the context of the meaning assigned to disability as well. For example, in many societies, the wheelchair is a symbol of disability and thus wheelchair users may be assigned certain meanings by society (Pettersson, Appelros, & Ahlstrom, 2007). Conversely, walking devices such as canes may be less stigmatizing, perhaps because of their mainstream use (Pettersson et al.). In Western society, although devices such as computers and cell phone draw very little attention to the user because of their commonplace use (Hoppestad, 2007), higher technology communication devices may serve to be the most stigmatizing

of all AT perhaps due to the synthesized voice (Lupton & Seymour, 2000). The findings of a qualitative study of families of children who use AAC devices suggested that some families held specific concern around the “double stigma” that their children would face as a member of an ethnic group and a child with a disability (Parette & Brotherson, 2000, p.185). These parents felt that their child would gain further unwanted attention if he or she were to use an AAC device. Thus, using this particular AT would not enhance the psychological well-being of these parents.

AT has also been described as a means to circumvent environmental barriers (Pape et al., 2002). This touted benefit also needs to be considered within a cultural context. Even in North America, it is evident that there is often a lack of congruence between AT and the environment. For instance, some AT does not withstand extremely cold climates or is not appropriate for use by those who live in rural and remote locations where services such as road maintenance and clearing, sewer systems and electricity and computer and internet access are absent. This lack of contextual congruence is illustrated in the study by Wearmouth and Wielandt (2009) who conducted a phenomenological study of seven First Nations people with spinal cord injuries living on a reserve in Canada. Study participants reported considerable accessibility issues within their own homes and in their communities with unpaved roads. They identified that the majority of public buildings where cultural ceremonies took place could not accommodate wheelchairs: in this case, the AT (wheelchair) did not always serve to support cultural activities due to environmental barriers.

Another benefit of AT extolled in the literature is the ability of AT to reduce reliance on families or caregivers; for example, Hoenig, Taylor and Sloan (2003) demonstrated that the use of AT reduced the number of personal assistance hours required among elderly community living individuals. Although health care cost savings are valued in Western society, if the family culture is to provide that assistance, AT may represent a threat to the relationship and role of the family member as care provider. Moreover, the interdependence of family members and individuals is particularly salient with respect to AT use. Family members may be involved in providing assistance, set up, repairs, repositioning or taking care of the device on behalf of the user (Parette, 1999). In particular, parents and spouses of individuals with disabilities are integral to AT use; use of AT will change family routines and habits (Parette). Recognizing this interdependence and exploring the impact of AT within the family context is essential.

Increased social participation is another purpose of providing AT. Of all of the AT devices provided, augmentative and alternative communication devices (AAC) may be most highly influenced by cultural diversity, as language is intricately associated with the social construction of culture (Burr, 2003; Hasselkus, 2002; Trembath, Balandin, & Rossi, 2003). AAC may be developed and programmed without considering how to include culturally appropriate language and symbols in the device (Trembath et al.; Ried et al., 1995). Rather than promoting social participation, this ethnocentric action may result in the alienation of the AAC user (Hetzroni & Harris, 1996). As social participation occurs within the context of one's immediate culture, as well as within the dominant culture, the AAC user requires linguistic and social communication competence that

crosses both cultures (Hetzroni & Harris). In an ethnographic study of four Mexican-American families of children who were AAC users, McCord and Soto (2004) identified that most families used the AAC device in specific environments such as community settings. At home, despite the fact that participants were able to express more complex thoughts and ideas using the AAC, families elected not to use the AAC device as they perceived the language programmed into the device to be inconsistent with their preferred style.

Thus, the compatibility of the AT with the individual and/or families value and belief systems must be foremost (Parette, 1999). Moreover, the cultural meaning ascribed to AT may ultimately relate to the issue of AT abandonment. If AT is prescribed with a Western view of what it will accomplish and consideration of the cultural context is dismissed, AT service providers may be failing to meet the needs of their clients.

### **Cultural perspectives on AT service delivery**

In addition to considering the client's beliefs about disability, meaning of AT and sociopolitical history, AT providers need to consider their own cultural-situatedness or the historical and social positioning of clinician and client (Lomay & Hinkebein, 2006). AT providers need to be reflexive in their practice, to avoid imposing their own cultural values on the meaning and use of the AT (Harry et al., 1999; Parette et al., 2003). There is a need to go beyond sensitizing AT providers to the practices of individuals of different cultures, to develop a comprehensive understanding of the meaning and implications of the AT held by the individual, family and social group. This understanding needs to be

balanced by a self-recognition that one's view is only one of many (Harry et al., 1995) and that knowledge and belief systems are relative to the ways that he or she view the world (Burr, 2003). In particular, developing a "posture of AT cultural reciprocity" may be useful in moving the provider from awareness to application (Parette & Brotherson, 2004, p.360). In developing a posture of AT cultural reciprocity, service providers tease out the underpinnings of their own set of beliefs and values rather than assume that they represent a universal belief system. Through this process, professional values and assumptions are highlighted, an understanding of how family perceptions of AT differ from those of the professional is developed and AT interventions that address the family's value system are used (Harry et al., 1999; Hetzroni & Harris, 1996). The process of developing a posture of AT cultural reciprocity can be further enhanced by integrating the concept of cultural safety. Culturally safe frameworks are critical frameworks that analyze the power relationships between health professionals and the people they serve, including examination of the taken-for-granted assumptions of health care professionals (Richardson & Williams, 2007). In practicing in a culturally safe way, there is recognition that each person holds their own unique cultural identity. Cultural safety requires AT providers to critically consider the dominant social discourse that influences their thinking and practice (Browne, 2009). Adopting a posture of AT cultural reciprocity, and operating within a culturally safe framework, prevents the tendency to view an AT user as 'the other' and reinforces the need to recognize that each hold our own set of attitudes, beliefs and values.

## **Disability as Culture**

Perspectives on disability are shaped by cultural beliefs and understandings, and as a group, people with disabilities share a culture when disability becomes an identifying characteristic and a source of pride (Devlieger, Albrecht, & Hertz, 2007; Tower, 2003). To provide culturally appropriate AT services, it may also be important to understand the extent to which an AT user identifies with a disability culture. Similar to other perspectives of culture, there are varied views of disability culture; however, it is clear that disability culture is different than exploring how people of different ethnicities view disability (Brown, 2002). Disability culture develops within a group of people who hold a particular worldview about disability, experience a common sense of alienation and who develop shared language and community (Devlieger et al.).

Peters (2002) suggests that there are three distinct worldviews on disability culture: historical/linguistic, socio/political and personal/aesthetic. Rather than a dynamic process, historical or linguistic culture is received. Within the disability culture, this aspect is evidenced by common language and history, existence of a cohesive social community, political solidarity, and acculturation with the family, genetic links, a sense of pride and identity (Tower, 2003). Culture as sociopolitical refers to the coming together of disabled people around a common goal, based on a desire to address issues of struggle, stigmatization, discrimination, oppression, and asymmetrical power relationships; the sociopolitical view of disability culture is equated with the social model of disability (Kirshbaum, 2000). Culture as personal or aesthetic refers to the personal interpretations of life and social experiences as encountered through the body. There is a

subsequent development of a cultural identity as a disabled person and a search for answers to the questions ‘What is the importance assigned to disability? By whom?’ (Peters, p.595). Disability portrayed as part of the human experience in film, music, media and art are forms of the personal or aesthetic expression of disability culture (Brown, 1997).

Within the disability culture, there is a strong call to present art, history and literature that portrays disability as a natural part of the human experience. Although the past tendency has been to perpetuate stereotypes of individuals with disabilities, there are efforts underway to reduce stereotyping in the media that victimizes, demonizes or patronizes the individual with a disability and a shift to recognizing disability as a natural part of the human experience (Broadcasting and Creative Industries Disability Network, 2007). Peters (2000) concludes that disability culture is formed by a syncretisation of these worldviews, and that the existence of all three perspectives provides evidence of a culture of disability.

Yet, within academic and professional literature, there has been substantial discourse about the existence of a disability culture. Disability culture seeks to identify disability as a defining characteristic of an individual rather than promoting similarity along other important characteristics such as age, gender, or ethnicity (Hammell, 2006), but not all individuals agree with the political nature and social action intent behind the development of disability culture.

Nevertheless, disability is one important dimension of the human experience and thus understanding the belief and value systems of how and why individuals identify with a particular group is essential. For individuals indoctrinated in a disability culture, the use of AT may serve as a means for participation in society. Tower (2003) asserts that AT is a part of adaptation, which is one of several groups of strategies that have emerged within the disability rights movement. In effect, AT has been considered to be one of the “great equalizers in education, employment, transportation and social life” (Tower, p.19). AT can be used as a means to address marginalization (Lupton & Seymour, 2000), a tool for empowerment (Kirshbaum, 2000; Parnes et al., 2009), and a mechanism for achieving full citizenship (Seelman, 2006); all constructs that are consistent with a disability culture perspective.

### **Conclusions and need for further study**

In conclusion, it is evident that, although utilized by an individual, AT use occurs within a much larger socio-cultural environment (Lupton & Seymour, 2000). There is a paucity of knowledge about the intersection of AT and culture; this intersection requires further study (Pape et al., 2002; Parette, 1999; Trembath et al., 2005). The cultural belief systems of all stakeholders, including clients, families, communities and professionals, need to be examined and appreciated for their unique and inter-related influence on how AT is perceived and used.

It is essential that service providers clarify individual and family beliefs in terms of what they expect the AT to do for the individual, how it will work and how it will fit



into the client's social and cultural environment (Parette & Brotherson, 2004). Using frameworks such as the questions related to meaning and consequence of disability, adopting a posture of cultural reciprocity and incorporating concepts of cultural safety into practice is imperative so that AT service providers can best meet the needs of their clients. Active knowledge translation strategies, such as the use of e-learning resources, have been identified as a mechanism that can meet the learning needs of rehabilitation professionals (Menon, Korner Bitensky, & Straus, 2010). These types of resources could be developed within the AT field to engage providers in discourse around how culture is conceptualized and addressed in the context of assessment and delivery of AT.

Existing AT research conducted to explore socio-cultural issues, meaning and use of AT has generally been ethnocentric in nature, examining the use of AT in 'the other' (Richardson & Williams, 2007). Adopting an ethnocentric view fails to recognize that the health care culture is foreign for most individuals while their own cultural perspective is the norm (Richardson & Williams). Studies that attempted to identify the unique influence of race on AT use are equally problematic. Although somewhat useful in examining dominant cultural forces, the challenge is not to allow this type of data to contribute to the perpetuation of generalizations that prevent exploration of the underlying constructions of disability within individuals, families, and communities. Some qualitative studies have attempted to explore individual meaning and perception; however, most have not done so with a cultural lens. Future research should be conducted into the meaning of AT among individuals who share common belief and value systems, and situated within the social, political, geographical and economical contexts that

influence their opportunities and decisions. Addressing these research and practice issues is a considerable, but essential, responsibility in a field such as AT that seeks to provide service to a heterogeneous population. In countries that are becoming increasingly culturally diverse, AT service providers and researchers can serve as catalysts in this exploration by valuing diversity in their clients while maintaining reflexivity.

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## **Chapter 8: Link to Chapter 9**

The perspective brought forward in the Chapter 7 on understanding assistive technology meaning is further explored in Chapter 9: *The Role of Assistive Technology in Self-Perceived Participation*. The specific strategy category of assistive technology and adaptations identified in the grounded theory study described in Chapter 5 was deconstructed in light of the individual meaning that people in a specific socio-cultural context place on their AT. Study findings in the latter chapter identified how participants frame or position their AT and the meaning they ascribe to their technology in order to engage in a process of participation. The meaning ascribed was elucidated through the decision-making processes they engage in as they select and use their assistive technology. This chapter concludes by establishing the need to revisit existing definitions of AT and to develop a contemporary definition that is consistent with developing notions of the role of AT in self-perceived participation.

## **Chapter 9: The role of assistive technology in self-perceived participation**

In Canada, 4.4 million Canadians are living with a disability (Statistics Canada, 2008a) and 42% of Canadian adults aged 15-64 who reported having a disability identified using adaptive aids and equipment (Statistics Canada, 2008b). Some research findings support assistive technology (AT) as one of the greatest facilitators for individuals with disabilities (Boschen, 2003; Dattilo, 2008). For instance, in a survey of 357 members of the British Columbia Paraplegic Association, 20% identified AT as one of the primary supports for participation in social and community activities (Carpenter, 2007). In contrast, the complexity of devices, time required to use AT, and potentially negative impacts on self-identity can create challenges for the AT user (Copley, 2004; Dattilo, 2008; Lindstrand, 2002; McMillen & Soderberg, 2002; Ostensjo, 2005).

Currently accepted and often cited operational definitions of AT are shown in Table 1. In each definition, the primary focus is on using AT to improve functional performance; a statement also frequently supported in the AT literature (e.g., Cook & Polgar, 2008; Isabelle, 2002; Johnson, 2007; Judge, 2002). However, the definitions have been critiqued as narrow in focus as they preclude considering how AT might be used to enhance behavioural or social functioning (Edyburn, 2003). Correspondingly, there has been the shift in the AT lexicon over the past two decades, from describing AT's primary purpose in terms of remediation of an individual's impairments, to discussing how it promotes ability to engage in activity, to the current emphasis on the social aspects of functioning and participation that can be realized through AT use (Boschen et al., 2003; Campbell, 2008; Copley, 2004; Jirikowic, 2003; van de Ven et al., 2005). Although it is



often assumed that AT use has a positive effect in promoting participation (Harris, 2007; Jirikowic, 2003), a paucity of research exists that explores this assumption. In fact, few outcome studies have specifically investigated the role of AT in improving participation (e.g., Gentry, 2008; Jedeloo, 2002; Pettersson, 2005; Tam, 2005; Vincent, 2007).

Furthermore, drawing definitive conclusions on the role of AT based on these studies is not possible due to heterogeneity in the population (age, disability), type of AT used, and use of outcome measures that were not developed with a theoretical basis specific to the construct of participation.

Aspects of the process of participating include those aspects that make up the dynamic interaction between the person, environment, and AT. The integration of these components is well-accepted in the field of AT as a framework for decision-making as to whether an individual will successfully use the AT (Cook and Polgar, 2008; Fuhrer, 2003; Scherer, 2002); Noreau et al. (2005) propose that the interaction of these factors plays a role in self-perceived participation. Moreover, AT devices hold unique meaning to their users, shaped by the users' inter-subjective experiences within their particular social and physical environments. The assigned meaning of AT is anticipated to hold both unique and shared meanings for participants, influenced by the environments and events that people experience as individuals and as a part of community life (Berg, 2001; Dietz, 1994). Despite this assertion, there is a noticeable lack of acknowledgement of either the transactive nature of AT and the environment or the role AT plays in promoting participation in current definitions of AT.

Recent advances in technology and the concomitant focus on participation as a rehabilitation outcome have made decision-making around appropriate AT more complex. As improving participation has been identified as an ultimate aim of rehabilitation (Cardol et al., 2002; Chan & Chan, 2007; Coster and Khetani, 2008; Gray et al., 2006; Noreau et al., 2005; Perenboom and Chorus, 2003), an understanding of how AT factors into the experience of participation is needed. Learning from the experiences of AT users will contribute to the understanding of AT service providers, ensuring recommended AT devices promote participation within families, communities, and society.

The purpose of this paper is to develop an understanding of how AT factors into self-perceived participation for individuals with spinal cord injuries (SCI). In doing so, a revised definition of assistive technology will be proposed that includes participation as a person-centred outcome. In Ripat and Woodgate (2011), a grounded theory model of the participation experiences of adults with SCI was constructed, with AT use emerging as one of four strategies individuals used to engage in the process of participating. In that study, participation was described as the consequence of negotiating a body-environment interface, and consisted of four sub-categories: Accomplishment, Autonomy, Inclusion, and Reciprocity. This research report presents the findings that related to one of the sets of strategies that participants used in their participation experiences, called “Assistive Technology and Adaptations”. In this report, this latter category is deconstructed to better understand how individuals use AT as a strategy for self-perceived participation.

## **Methods**

This study was guided by symbolic interactionism, an interpretive approach that suggests the meaning ascribed to society and reality are constructions of a dynamic interaction between the individual and the social structures that are a part of their life-world (Berg, 2001; Charmaz, 2006; Prus, 1996). We used constructivist grounded theory (Charmaz, 2006), in which researchers and participants co-construct the meaning of data collected, to develop a descriptive and interpretive theoretical rendering of the experiences of participation as shared by the participants.

First, in-depth intensive individual interviews were held with each participant. The first author (JR) conducted all interviews in the study, and field notes were taken at the conclusion of each interview. All interviews were digitally recorded and transcribed in full. The intent of the initial interview was to gain an understanding of each individual's story and experience of disability, and to gather rich and detailed descriptions of the meaning and experience of participation. Next, photovoice (Strack, 2004; Wang, 1997) was used to capture participants' insider perspective regarding participation. The photovoice data collection method consisted of providing participants with digital cameras to photograph relevant individual, family, and community life experiences to illustrate social and community participation. Cameras were adapted as needed to ensure participants could use the cameras independently. Participants then selected photos that best represented their participation experiences and brought these to a second interview, where discussion focused on the meaning of the photos to the

participants. Finally, participants were invited to attend a focus group to discuss, interpret, and contribute to the overall credibility of findings.

Data analysis was undertaken with an aim to “make fundamental processes explicit, render hidden assumptions visible, and give participants new insights” (Charmaz, 2006, p.55). For this portion of the study, categories that related to AT were extracted from the full data set and analysed. A process of constant comparative analysis was used, initially comparing data within an interview in the initial coding phase, then comparing the data from a participant’s initial and second interviews, and then comparing data from one participant with that of other participants. Lastly, categories were examined for their developing relationships between categories (Charmaz).

Trustworthiness of the data was addressed in multiple ways. Triangulation of data was used to gain a comprehensive and complementary picture of participant experiences. Through prolonged engagement in the study, participants and the researcher developed a relationship that promoted feelings of trust and sharing. The first author kept a research journal to reflect on biases and assumptions that emerged which was used throughout the inductive analysis process. The second author, additional peers, and participant member-checking verified the interpretation of data and the findings (Law & McDermid, 2008).

The study was approved by the University of Manitoba Health Research Ethics Board and all participants provided informed consent prior to data collection; as data collection occurred over a prolonged period (up to 12 months), on-going process consent was also verbally obtained prior to each participant encounter. Participants received an

honorarium for each interview completed, and participants kept the digital camera and associated adaptation devices upon exit from the study.

## **Results**

Nineteen adults with spinal cord injury were recruited into this study. Table 2 shows demographic characteristics of participants. The primary theme identified in this portion of the study was titled “AT as a means to participation”. Three categories related to the primary theme- *Inclusion versus Autonomy and Accomplishment, Availability and Cost, and Considering Contexts of Use*– and served to identify the decision-making processes that individuals underwent to select AT that would promote positive participation experiences. In the following section, selected quotes and photos are used to illustrate how participants characterized each category.

### **AT as a means to participation**

AT was central in the lives of study participants in terms of being able to engage in community life. Participants spoke of “freedom”, “independence”, “a means to do something that is difficult”, and “opening up opportunity” in reference to AT. The importance placed on AT was clearly articulated by one participant, David (Figure 1).

For study participants, participation was self-perceived, and expressed as an experience rather than an activity or role they engaged in. AT use enabled participation experiences of autonomy, accomplishment, inclusion, and reciprocity (Ripat & Woodgate, 2011). When asked to share an example of participation, Wilson selected to share his experience of playing on a sledge hockey team, describing how being involved

on that team supported his feelings of belonging, being a part of something, and being active and how the technology (the adapted sledge) provided the means to this meaningful activity (Figure 2). Similarly, Vern, who had lived in an institutional setting as a child, recounted how receiving his first power wheelchair led to an increased sense of participation:

But I get this electric wheelchair, suddenly I can go down the hallway and I can visit anybody and I can, I can go from one room to the other and, and one of the cool things was you could run errands for other patients...so suddenly you can take something they need taken from one room to the other, or take something downstairs, so yeah so, so suddenly, suddenly you're useful and independent.

Participants in this study did not view all of their AT devices in the same light; rather different attributes of participation were highlighted as valued when relating to different devices. For some AT was a means to participation, whereas other devices were viewed as an end in themselves. For example, Fynn assigned a pragmatic meaning to his manual wheelchair, describing it as the one he uses to “get strong with” (accomplishment) and his power wheelchair as representing “freedom” (autonomy).

AT provided a means to engage in activities of importance. In particular, participants highlighted leisure engagement and driving as activities that required AT, and in which engagement provided inclusion, accomplishment, and promoted ones' self-identity. Participants submitted photos of adapted curling devices, sledge hockey, adapted sailboats, fishing, and hunting devices. Jayna and Garrett each highlighted the importance

of an adapted bicycle and how the device allowed them to participate with their children in this everyday activity. The possibilities afforded by emerging technologies were identified; David, who sustained his SCI 20 years ago, identified how newer AT such as wheelchairs with large sand-capable wheels and accessible weight lifting equipment were important developments. Having access to one's own wheelchair accessible vehicle was indispensable for engaging in community participation for many, as expressed by Reed (Figure 3).

Whether or not they were the driver, having access to an accessible vehicle allowed for independence, control, and convenience that was not afforded by public transportation. Tom stated: "it's a world of difference having your own vehicle, just get up and go when you want to."

As participants engaged in a process of life and community participation with their AT, they made various decisions in selecting the most appropriate technology to facilitate participation. The decision-making processes described by study participants addressed different aspects of the environment, including the social and attitudinal, policy and funding, and the natural and physical.

### **Inclusion versus Autonomy and Accomplishment**

Participants described the process of selecting AT based on creating a balance between the stigma they perceived to be associated with a device weighed against the function and autonomy that they felt they were able to achieve with that device.

Wheelchairs, as the most common AT used by people with SCI, was often the AT under

discussion. Often, these two perspectives were in conflict and they needed to reconcile which of the two was more important:

JR: So do you see the power chair as a more obvious kind of technology?

Reed: Um. Yeah I, I'd like to avoid it [power wheelchair] as much as possible. I don't, maybe it's just my head, I don't know...um, even something like having a camera that's covered in Dycem [rubberized material], it's just, it's not the ideal I guess, but if it's more functional, um I'll just, I'll use it...it's just, the less, the less I can get away with I try to, I guess. I don't know why. Just trying to fit in and be normal, whatever.

For Reed, who was striving to minimize his obvious use of technology, the use of a manual wheelchair helped him to maintain his identity consistent with what he perceived a less disabled person would look like. For some, the power wheelchair was more stigmatizing than a manual wheelchair and was thus less socially sanctioned. Participants explained how society in general also shared this perception with them, the latter suggesting that people would become idle by not using a manual chair and that the power chair was the easy way out. Individuals perceived substantial societal pressure to maintain strength and endurance through manually propelling a wheelchair, despite the fact that it was difficult or painful for them. This pressure was internalized early; Harrison, who had sustained his SCI one year ago, stated, "Like, if I can use this chair [manual wheelchair] I do. I don't like just sitting in the power chair is kind of, I don't know, you get lazy I guess."



However, although many initially selected a manual wheelchair on the advice and social pressures of others, the importance of autonomy often overrode that decision at some point, as Andrew shared:

See I know when I was first in a wheelchair everybody says oh you never want to go into a power chair. And uh so the first couple of years I didn't, and just living in the country and going out on the lawn you know I had to get my wife to push me out here and you know I couldn't move around on the lawn I couldn't anyway, I don't know what other people do...well just on grass hey, with a regular chair. It wasn't an outdoor chair and uh so after a couple of years of that I had it, I said enough of this, just because uh you know and I mean now I can go where I want. When I want. You know if my heads burning in the sun I can go in the shade. I don't got to get somebody to push me around there ...I can go a lot more places with this than I could with the other.

Similarly, for those who had a choice between walking with aids or using a wheelchair, what began as a socially sanctioned decision was sometimes overridden by the need for autonomy, convenience, and efficiency. Jayna, who had her SCI as an infant, began walking with orthoses and gait aids at her family's insistence but exerted her autonomy as she moved into adolescence:

Jayna: When I was a teenager, I opted for a wheelchair.

JR: Um-hmm. Do you still use crutches?

Jayna: No, no. Once I left them it was... it was like I, I didn't like them but my grandmother you know she insisted that she's going to walk type thing... I said I want a wheelchair cause like then I could go with my friends, I could go anywhere you know.

### **Availability and cost**

Availability of AT and AT funding factored into decision-making. When not commercially available, some participants were involved in creating their own AT to meet their specific needs in a creative way. For example, David discussed how he put a thermometer inside his shoe to monitor his foot temperature to prevent his feet freezing due to lack of sensation, and stated he came up with his own solution as “no one is going to do it for me.” Others collaborated with engineers to come up with unique solutions to the issues they faced (Figure 4). However, this created a problematic situation for some as there was believed to be a lack of qualified engineers to meet the ongoing AT developments: “it's the rehab engineer not having the manpower to keep up with the technology” (Vern).

The high cost of AT factored into decision-making around purchase or repair of devices. Participants highlighted how medical devices are always more expensive than comparable devices; for instance, Garrett pointed out that the cost of a wheelchair bolt was much greater than those created for farm machinery, and thus selected the latter to use as replacements for his wheelchair. Participants used the Internet to source out the best prices for AT, and selected items in part due to their affordability.

When third party funders, such as insurers, were involved, they were perceived to hold substantial decision-making power over the AT purchase. Despite the importance placed on leisure adaptations by participants, leisure items were not perceived as priority items by funders. Rather, items related to independent mobility, productivity, and independence were prioritized. This resulted in participants typically having to self-fund expensive and often untenable equipment. Garrett waited many years to purchase the adapted bicycle he wanted (Figure 5).

### **Contexts of use**

Participants relayed how anticipated environmental demands were a primary factor in making decisions about which AT to select. AT was selected to overcome barriers in the built, geographic, and climatic environments (Figure 6).

When faced with going to an environment that was unknown in terms of its accessibility, participants made decisions based on a default assumption of inaccessibility. For some, this meant using a manual wheelchair to make it easier to be lifted up stairs or over doorstops. Marlene shared:

The wedding was up here and at the time, all the chairs were here [up a set of stairs]. So they pulled me up the stairs for the wedding. So I had to make sure, because I wasn't sure, I came in my manual chair. If I'd have come in my power chair I would have had to stay back.

Wilson summarized the impact of environmental accessibility on his perception of the meaning of AT: “[the wheelchair provides] freedom in that I can get out the door... but it’s a restriction if you come across an elevator that's at the top of a stairwell.”

### **Discussion**

In this study, the focus on lived experience as shared through interviews and photos formed the basis of self-perceived participation in which activity was experienced and assigned meaning through interaction within the environment (Dietz et al., 1994; Prus, 1996). For many participants, the use of AT was highly linked with a variety of participation experiences, promoting participation in those occupations that held personal meaning and importance. Similar to other studies, the importance of having access to private accessible transportation in terms of convenience and autonomy was highlighted (Boschen et al., 2003; Carlson and Myklebust, 2002; Ville et al., 2003; Wee et al., 2009). Meaning ascribed to AT in general such as freedom and opening up of opportunities were similarly found in a qualitative study by Reid, Angus, McKeever, and Miller (2003), in which women wheelchair users called their wheelchairs *liberators* as they enabled independence with desired occupations.

Decision-making around choice of AT addressed capacity to influence ones’ self-identity, pragmatic issues of cost/funding availability, and contexts of use. Participants in the current study placed little emphasis on physiological considerations such as pain, positioning, or pressure management. It may be that physiological issues had been adequately addressed in the initial procurement process and were no longer the deciding

factor in terms of device use, or that they were less of a concern for AT users than for service providers (Batavia et al., 2001; Mortenson and Miller, 2008). The meaning of AT to the individual in terms of capacity to influence self-identity and to fit into societal expectations has been highlighted in previous research as key to decision-making around AT use (Copollilo, 2001; Hocking, 1999; Louise-Bender Pape et al., 2002; Lupton & Seymour, 2000; McMillen & Soderberg, 2002; Mortenson & Miller, 2008). This finding was also prominent in the current study, and thus the findings of this study support the use of outcome measures intended to tap into the impact AT has on psychosocial aspects of the person.

Whereas most discussion of AT decision-making frameworks identify the need to consider unique attributes of the individual (e.g. Batavia et al., 2001; Cook and Polgar, 2008), our findings suggest the inter-relationship between AT and self-identity must be a foremost consideration. Preservation of self-identity, through minimization of stigma, enhancement of autonomy, or overcoming environmental barriers, seemed to occur during device selection, when a choice was available. The current study's relative hierarchy of acceptability of AT device use has also been reported by Copollilo (2001), who found that participants who used a cane for mobility predicted they would find it "unbearable and devastating" (p. 195) to move to permanent wheelchair use whereas permanent wheelchair users reported their wheelchairs were useful, rather than stigma-producing, devices. The Psychosocial Impact of Assistive Devices Scale or PIADS (Jutai & Day, 2002) is a standardized self-report measure with well-developed psychometric properties that addresses factors related to constructs of adaptability, competence, and

self-esteem. Using a measure such as the PIADS would enable clinicians to understand meaning ascribed to a device and device users to discern how the use of different AT may affect their self-identity.

Cost was a consideration primarily for those items that were seen as a luxury to funders (i.e., recreational equipment). The value of leisure-based AT does not hold the same prominence in western society as does AT for productivity. Family and community participation in recreational activities are often seen as luxuries and people generally needed to find their own funding to support these activities. Similar to the findings of Ripat and Booth (2005), AT that promotes self-actualization or self-esteem was not valued by funders to the same level as that which promoted productivity and autonomy. The importance of engaging in leisure activities for mental health benefits, well-being, self-actualization, and self-identity is apparent (Majnemar, 2010) and evidence to support the value of leisure for individuals with SCI exists (Beringer, 2004; O'Brien et al., 2008; Schmidt Hanson et al., 2000). However, this evidence has not translated into client-centred funding policies that value leisure participation at the same level as employment or education. It is apparent that western values of independence, autonomy, and productivity are perpetuated in funding policy, allocations, and decisions.

Learning about the environment of use has been highlighted frequently in decision-making frameworks (e.g., Batavia et al., 2001; Cook and Hussey, 2008). However, knowing about the environments of use is not enough to know how people will choose their AT; rather it is understanding the potential environments, in combination

with the primary occupations that they are, would like to, or anticipate, engaging in. As stated by Mortenson and Miller (2008), “Wheelchairs represent sites where occupational engagement, self-identity, and the cultural and physical environment are negotiated” (p. 174). Overall, the prominence of all aspects of the environment (social attitudes related to self-identity and perpetuation of societal values, physical built environment, climatic, and geographic accessibility, and the policy environment) were highlighted as contributing to decision-making around AT. From the AT users perspective, their unique environments and occupations of choice impacted selection of AT, ultimately leading to a positive sense of self-perceived participation. The three decision-making categories in the current study are consistent with the findings of a study examining the process of wheelchair procurement (Mortenson & Miller, 2008), in which participants identified how accessibility, self-identity, society’s attitudes, and funding were all key aspects of the environment that influenced decision-making around wheelchair selection.

When the AT selected promoted a positive self-identity and had congruence within the unique environmental context, that AT could be used for occupational engagement and performance (Polatajko et al., 2007) in order to experience a positive sense of self-perceived participation. When the AT did not promote a positive self-identity, and/or there was contextual incongruence with the AT, it would not be used for the same positive participation experience. Based on the findings of this study and the supporting and related literature, we have developed a new definition of AT that privileges user-centred outcomes of participation (Fuhrer, Jutai, Scherer, & Deruyter, 2003). Furthermore, this definition is in keeping with the United Nations Convention on

the Rights of Persons with Disabilities (United Nations, 2007), that supports the use of AT as a means for full inclusion and participation of persons with disabilities (Borg, Lindstrom, & Larsson, 2009). In contrast to function-focused definitions, the proposed definition highlights the relevance of the context or environment as well as the importance placed on an outcome of person-focused participation. The proposed definition is:

Devices or adaptations that serve as an interface between people with disabilities and their unique environments, used to engage in occupations of choice, and to promote self-perceived participation.

### **Clinical implications and conclusion**

The results of this study highlighted the role AT plays in terms of self-perceived participation of individuals and reinforced the importance of the environment in contributing to AT use. A new definition of AT has been proposed; this definition includes a broader perspective of the use of AT than purely for functional usage. Finally, the results of this study point to several key questions that could be discussed with the individual AT users' in decision-making around AT. Specifically, these questions include:

- (How) does the AT promote positive self-identity?
- What is the contextual congruence with the AT in terms of the individual's self-identified environments of use, perception of societal sanctions, and access to the desired device?



- (How) does the AT promote engagement in, or performance of, meaningful occupations of choice?
- How does use of the AT device contribute to a positive sense of self-perceived participation (e.g., inclusion, accomplishment, autonomy, reciprocity, or other)?

In some cases, assessment tools and outcome measures are already developed, or under development, and available to address these key questions. For other questions, there is a need to develop or adapt tools, or create new methods that can capture these perspectives.

Although not explicitly directed to do so, participants in this study primarily discussed AT that they used in community settings rather than AT used for personal or intimate use (such as self-care equipment). Furthermore, all participants had SCI and thus are not representative of the range of experiences of all people with disabilities. The study was conducted in one Canadian province where, although socialized health care exists, funding for AT is inconsistent with some individuals receiving public funding, and others receiving third party funding for their AT (Ripat & Booth, 2005), leading to differences in AT availability and access. Finally, this study did not address a procurement stage of AT use, rather participants were experienced and competent AT users at the time of study enrollment. The perspective of an experienced user may prioritize subjective well-being and psychological functioning over concerns around effectiveness or efficiency; the latter may have been of greater importance at the procurement stage (Fuhrer et al., 2003).

Despite these limitations, this study proposes a move forward in understanding the role of AT in the lives of AT users. Future research with a broader demographic group of AT users is required to further develop the definition proposed in this study, followed by examination of how this definition resonates with other stakeholders. Foremost, we must draw on what we learn about the aspects most important to consider for, and from, AT users in this process.

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**Table 1. Assistive Technology Definitions**

<p>“all specialized aids, devices or services that enable persons with disabilities to carry out their everyday activities, such as by making it easier for them to get around (wheelchair, hand or arm support) or by helping them to hear, see or speak (hearing aid, Braille reading materials, keyboard device for communicating)” (Statistics Canada, 2008b)</p>
<p>“any piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase, maintain, or improve functional capabilities of individuals with disabilities” (Tech Act, 1998).</p>
<p>“any product, instrument, equipment or technology adapted or specially designed for improving the functioning of a disabled person” (WHO, 2011)</p>

**Table 2. Participant Demographics**

Gender	
Male	n=13
Female	n= 6
Age range (years)	
20-39	n=7
40-59	n=11
60 +	n=1
Nature of SCI	
Traumatic	n=15
Congenital/disease	n=4
Level/type of injury	
Tetraplegia	n=8
Incomplete	n=4
Living situation	
Owens home	n=11
Shared services apartment	n=4
Rents apartment	n=4
Social supports at home	
Lives with spouse or family	n=7
Lives alone	n=12

Vocation	
Post-secondary student	n=4
Full-time parent	n=2
Full-time paid employment	n=3
Self-employed	n=3
Volunteer/community work	n=7
Assistive technology use	
Manual wheelchair*	n=13
Power wheelchair*	n=7
Cane (+ knee/ankle foot orthoses)*	n=3
Bathroom/personal care equipment	n=19
Adapted vehicle (lift, hand controls)	n=8
Voice recognition software	n=5
Electronic Aid to Daily Living	n=5
Adapted recreational devices	n=6

\*Some participants used both a manual and power wheelchair, or canes and a manual wheelchair

**Figure 1.**

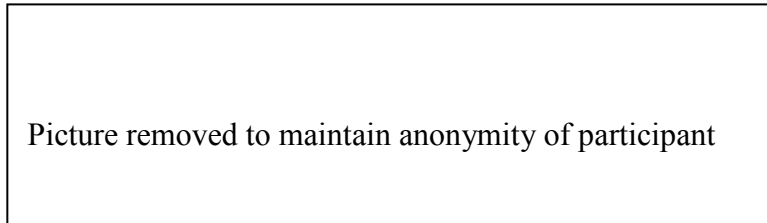


Figure 1. “[The braces] just really kept me going for 29 years...without them I would be totally lost.” (David)

**Figure 2.**

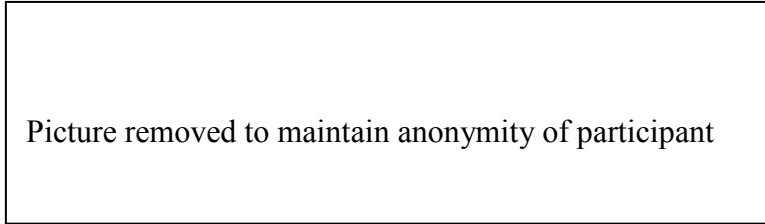


Figure 2. “So you know, the most important thing that I found is that at least I'm feeling part, part of something and that's what I've looked to sport for a lot of that...try to find the adaptations so that (a person) can participate” (Wilson)



**Figure 3.**

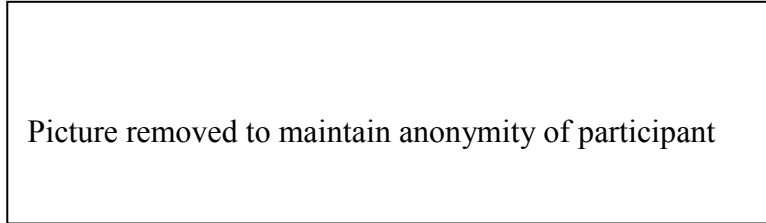


Figure 3. “[Hand controls are] by far the most important adaptive technology in terms of lifestyle enhancement.” (Reed)

**Figure 4.**

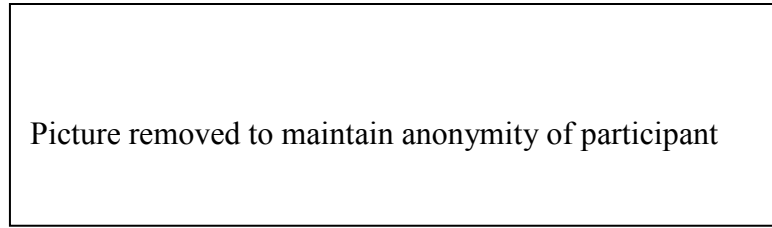
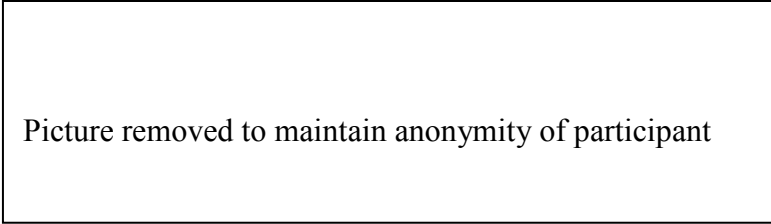


Figure 4. "So I have this hand warmer that I can carry around with me and it runs off of batteries under the wheelchair and it's very easy to turn on and it creates a lot of heat too...you know I used to be able to go out at ten above, now I go out at zero above because I know my, I know my hands are not going to get so cold they can't move..." (Vern)

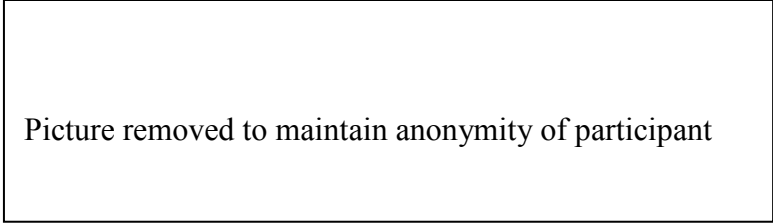
**Figure 5.**



Picture removed to maintain anonymity of participant

Figure 5. “With my sons getting older and stuff, I can't keep up with them in my wheelchair anymore. They're on their bikes. This just gives me that much more—I can get around with them and get good exercise. Because it's a medical supply the price usually jumps by a couple hundred percent.” (Garrett)

**Figure 6.**



Picture removed to maintain anonymity of participant

Figure 6. “I’ve taken my wheelchair like right down to the water edge and a little bit in the water. It has to be very sandy and very soft before I get stuck...it goes [through] snow perfect. Snow and ice. This is the chair” (Tom)

## Chapter 10: Introduction to Chapter 11

Review of the overall study findings, verified in the focus group and member-checking interviews emphasized the role of the environment in promoting and creating barriers to self-perceived participation. Throughout the study, participants did not discuss AT to the exclusion of other strategies they engaged in, or other supports and barriers to their participation, rather they placed equal primacy on the physical, social, institutional, and attitudinal environments. The findings reinforced one of the main tenets proposed by the social model of disability, i.e. that disability is a creation of structural factors and environments that result in the exclusion of individuals from full societal participation (Oliver, 1998). The study findings supported a need to draw on a critical perspective in research around the assistive technology-environment interface to frame the issue and identify possible solutions. Thus the fourth manuscript, *Locating Assistive Technology within an Emancipatory Disability Research Framework*, published in the journal *Technology and Disability*, is a critical exploration of the role that the social model of disability and emancipatory research methods may play in future research around assistive technology. The student wrote this article, while the student's advisor provided constructive suggestions on a draft of the manuscript.

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## **Chapter 11: Locating assistive technology within an emancipatory disability research framework**

### **Abstract**

Assistive technology (AT) provides an interface between a disabled individual and his or her environment. Historically, AT practice and research has focused on how a device can augment or replace the function of an individual, with less emphasis on how the environment creates disabling conditions resulting in the need to use AT. Researchers have primarily used positivist approaches to study the impact of an AT, although there has been a more recent inclusion of qualitative approaches. Emancipatory disability research, with a focus on empowerment, reciprocity, relevance, and action against societal oppression, has had a minimal uptake in the AT field and yet holds great promise for addressing the environmental aspect of the person-AT-environment interaction.

The purpose of this paper is to explore the congruence between AT, the social model of disability, and emancipatory disability research. The aim is to demonstrate that those in the AT field can benefit by adopting emancipatory principles and approaches in conducting research, developing new technologies, and providing services to AT users. Research that addresses individual impairments while addressing the environmental barriers that create disability can co-exist; embracing both views will be essential to the future of AT.

Key words: emancipatory research, social model of disability, assistive technology

## **Introduction**

Individuals with disabilities may use assistive technology (AT), such as mobility devices (wheelchairs, walkers, crutches), augmentative or alternative communication devices, computer access devices, and environmental control systems to maintain or augment their ability to interact with their world (Cook & Hussey 2002). As the environment becomes more technologically and socially complex, AT researchers, developers, and service providers indoctrinated in biomedical and rehabilitative models may be limited in their ability to explore the ways that AT and the environment that supports AT use can merge. Adopting different ways of examining the fit between AT and the environment in order to create an inclusive environment that promotes participation for individuals with disabilities is timely and essential. The purpose of this paper is to explore the congruence between AT, the social model of disability, and emancipatory disability research as one-step towards this more inclusive environment.

### **The social model of disability**

In the early 1980s, the *social model of disability* was introduced to contrast the traditional, biomedical model of disability with ways that society disables individuals through social, structural, cultural, and environmental barriers and exclusionary practices (Barnes, 2003; Barnes and Mercer 2004; Oliver, 1992). Based on foundational concepts of critical and emancipatory theories, this perspective reframed disability from viewing it as a problem of an individual to examining how structural factors and environments, such as social and political policies and practices, result in marginalization and exclusion of individuals from full societal participation (Oliver, 1998).

The social model proposes there is a clear distinction between impairment (biological) and disability (oppression) (Shakespeare & Watson, 2002). Within the social model of disability, *impairments* are the affected body structures, while *disability* refers to exclusion and oppression that result in the inability of an individual to participate fully in society. Thus, an individual may be *disabled* by the barriers created in the environment, such as the need to ascend a flight of stairs to enter a building (Barnes & Mercer, 2004). The social model of disability has been described as serving to “reverse this causal chain” that assumes impairment leads to disability (Barnes & Mercer, 1997, p.1).

At the core of the social model of disability is a political commitment to address oppressive societal practices (Barnes & Mercer, 1997). A focus on ensuring control of the decision-making processes that profoundly affect disabled peoples’ lives are in the power of the disabled person, and a concomitant focus on justice are hallmarks of this model (French & Swain, 1997). Empowerment and emancipation are key concepts: empowerment refers to the “process whereby people are enabled to take control of their lives”, while emancipation refers to “liberation from restrictions which is brought about by social change” (French & Swain, p.28).

The fundamental differences between the social model and biopsychosocial models (such as the International Classification of Functioning, Disability and Health from the World Health Organization) of disability result in selecting widely divergent interventions that are crucial to the discussion of AT for individuals with disabilities. If



the held belief is that disability resides in the individual, interventions will focus on modifying or adapting the person. Alternatively, if one believes that the environment creates disability, the intervention will be at the level of the environment. Therefore, within the social model of disability, intervention is targeted at the political and social level, not at the rehabilitation or medical level (Shakespeare & Watson, 2002). Within the more recent conceptualizations of the social model of disability, it is acknowledged that the appropriate intervention may be to offer therapeutic treatment when impairment is present (Barnes, 2003). This latter perspective proves particularly constructive when considering the use of AT and its possible congruence within a social model of disability framework.

### **Reframing assistive technology within the social model**

Traditionally, AT has been framed in biomedical terms. AT is designed to augment or replace a specific human physical (in)ability in order to enable performance of a particular task and ultimately to increase societal participation as is evidenced when we discuss the provision of a wheelchair as a means of replacing the need to walk. Within a biomedical framework, there is a focus on the impairment that creates the need for the device, rather than on the environmental barriers that initially created the issue (Orfanakos, 2006). However, taking the vantage point of the social model of disability, the use of AT may be seen as contradictory as it serves to exacerbate differences between people; highlighting some people as unique and different while simultaneously seeking to reduce differences by offering a means to increase societal participation (Armstrong & Fitzgerald, 1996; Hasselkus 2002; Lupton & Seymour, 2000).

In order to consider whether there is a viable fit of AT within the social model of disability, a process of reframing has been proposed (Oliver, 1992; Orfanakos, 2006). To begin this process requires acceptance of the contention that the structures of AT, disability, and rehabilitation are created and given meaning within the larger social context (Seymour, 2005) and that environmental barriers are the source of disablement. The field of AT provides several opportunities to reframe the location of disability from the individual to the societal level. When AT is viewed as a device situated at the interface of the body and environment (Brooks, 1998) and recognized as a means to support technological and social aspects of life (AAATE, 2009), reframing the location of disability to the societal level becomes logical. Adopting the perspective that impairment and disability are both legitimate aspects of an individual's experience, opens up the possibility of various forms of intervention that can occur at the "physical, psychological, environmental, and socio-political levels" (Shakespeare & Watson, 2002). Thus, use of AT may prevent *marginalization*, for example when disabled people use technology to access otherwise inaccessible environments (Lupton & Seymour 2000). The use of AT can be viewed as a means for *empowerment* when an individual has the decision-making power over use of the AT (Kirshbaum, 2000; Parnes et al., 2009). Furthermore, AT provides a means to communicate and move in ones' environment and thus can be used to address limited *societal participation* (Seymour, 2005).

### **Emancipatory disability research and assistive technology**

Disability theorists have described research as a dominant means of upholding and perpetuating oppressive and discriminatory practices (Oliver 1992; Vernon 1997) and

contend that the use of positivist and qualitative traditions of inquiry to study disability issues serves to create further disablement by alienating those researched from the process of research (Moore, Beazley, & Maelzer, 1998; Oliver 1992). Specifically, positivist and qualitative approaches promote a disparate relationship between those who conduct the research and those who are the object of research, further alienating the researched from the research process (Barnes & Mercer, 2004). Building on the social model and a growing discontentment that traditional social research served to perpetuate the oppression it was supposed to attenuate, emancipatory disability research was proposed as an alternate approach, namely one where the “social relations of research production” were challenged (Oliver, 1992). Emancipatory disability research focuses primarily on seeking to address issues related to “reciprocity, gain, and empowerment” within a political framework (Henderson, 1995; Oliver, 1992; Oliver, 1997; Zarb, 1992). This type of research seeks empowerment and emancipation both within the research process, and within society (Henderson, 1995). The primary purposes of emancipatory disability research are to shift the power balance within the research relationship to empower the disabled person to control the research process, to make disability research relevant to those who engage in the research, and to use the outcomes of research to highlight, confront, and challenge social oppression (Barnes, 2004; Barnes & Mercer, 1997; Barnes & Mercer, 2004; French & Swain, 1997; Hammell, 2006; Oliver, 1992; Oliver, 1997; Zarb, 1992).

Traditionally, health research has been framed around the individual or biomedical model of disability (Bricher, 2000; French & Swain, 1997; Orfanakos, 2006) and has served to redirect attention from the disabling societal barriers back to a focus on the individual's deficits (Orfanakos). The former perspective is consistent with AT research for the most part, which has tended to focus on how to use AT to "normalize" the disabled individual, overcome a disability, or replace function caused by an impairment. Furthermore, the conventional process of AT research has proceeded exactly as criticized by emancipatory disability research theorists; i.e. it has created a wide separation between the researcher and the AT user, where researchers have determined the research agenda and the AT user has been the object of that research. The limited use of emancipatory disability research methodologies in the field of AT is not overly surprising given the history of AT development and location of most service provision within biomedical institutions. The view of AT serving to replace or augment function is more closely aligned with the biomedical model than a model that seeks to address an oppressive environment.

Although different methodologies can be used within an emancipatory research framework, qualitative and participatory approaches are predominantly considered (Barnes, 1992; French & Swain, 1997; Mercer, 2004). Recently there has been an escalation of qualitative approaches used in AT as researchers and clinicians explore the individual experiences and meaning assigned to AT by technology users (e.g. McMillen & Soderberg 2002; Pape et al., 2002; Pettersson et al., 2005; Shepherd et al., 2007; Skär, 2002; Wiart et al. 2004). However, the vast majority of AT research has been conducted

using a positivist approach, and/or has not involved the AT user as a co-researcher and/or has not focused on addressing how social and political oppression creates disability, and thus the essence and intent cannot be considered truly emancipatory.

Participatory research (PR) has been proposed as a methodology to address some of the emancipatory goals of the social model of disability (Cargo & Mercer, 2008; Henderson, 1995; Letts, 2003). PR is distinguished from other types of research as there is a focus on capacity-building and empowerment with a primary goal of engaging those affected by the issue in the entire research process (Cargo & Mercer; Henderson). Furthermore, there is an expectation of a direct benefit to those involved in research, and that the knowledge gained will affect the issues identified by those participants in a way that is “in the hands of the people who need the knowledge” (Letts, p.79). The outcome of PR is intended to create an enhanced understanding of the social relevance of the issues and improved communication with and among government, policy makers, and organizations (Cargo & Mercer). However, it is unclear whether the use of a PR approach fully supports an emancipatory disability research agenda as while there is an attempt for reciprocity, full empowerment is lacking (Zarb, 1992). Indeed, as PR arose from qualitative methodologies rather than the social model of disability, and the primary focus is on the individual rather than the political, it is not surprising that it does not share the full emancipatory focus (French & Swain, 1997). For PR to be used within an emancipatory framework there is a need to move from disabled people *participating* in the research process to disabled people *controlling* the process (Zarb).

A paucity of AT research studies have identified taking an emancipatory disability research approach, using the social model of disability as a theoretical basis, or even drawing on participatory research methods to explore AT issues. In a study examining the social implications of wheelchair use, one group of investigators reported using the social model of disability to analyze findings of interviews of the wheelchair users, although the study was not staged in an emancipatory disability research approach (Sapey et al., 2005). In another set of studies, a group of researchers reported using a participatory action research approach to partner with adult consumers of an Independent Living Centre to gain an understanding of extent, use, and effectiveness of AT amongst its members (Kaye et al., 2008; Yeager et al., 2006). In these studies, representatives of the Independent Living Centre collaborated with researchers to develop the question and methods, conduct the study, and analyze the findings.

Other AT research that has adopted the use of participatory approaches has focused on the development of new AT (e.g. Blackstone et al., 2002; Mulholland et al., 1998; Sohlberg et al., 2003). However, some have contested whether the social model is able to adequately address the design issues needed to be considered for AT. For example, some researchers who have advocated for person-centred design contend that the “problem of design rests not on theoretical notions of how we define disability, but on ensuring the needs of the person are translated into appropriate design that should be empowering to the user” (Dewsbury et al., 2004, p.155). Overall, AT developers are faced with the challenge of creating technology that supports and empowers individuals rather than generating additional dependence and oppression.

Lifeworld, a methodology with phenomenological underpinnings, has been suggested as an alternate methodology for disability researchers that allows maintenance of the individual or subjective experience, while working within an emancipatory framework (Hodge, 2008). Lifeworld addresses the issue of disability research at the individual as well as the political level and explores both as “part of the lived experience” (Hodge). The use of a Lifeworld approach was used in a study of the meaning of AT for 22 individuals post-stroke (Pettersson, Appelros, & Ahlstrom, 2007); however the focus in this study was on understanding individual meaning and lived experience and thus was more closely aligned with an interpretive approach, rather than an emancipatory focus.

Although each of the studies discussed have some connection to an emancipatory disability research framework, it is clear that AT researchers have only engaged in the initial steps toward empowering disabled people to take full control of the research process. The goal of full participation of disabled people in the research process, as well as the broader goal of emancipation, remains unrealized in the field of AT.

### **The future of AT research and conclusion**

Thus, to date there has been little attention paid to the use of an emancipatory disability research framework in AT. Although this paper has provided an argument that the gap between viewing AT from an individual level and viewing it as a social inclusion and rights issue is narrowing, there is a need for further discourse on the issue. Clinicians, researchers, consumers, and policy makers need to engage in this critical, inclusive, and future-oriented dialogue. The continued need to provide AT to interact within an

inaccessible world does not mitigate the need to address the existent disabling social, political, technical and attitudinal barriers existing in the environment: we can simultaneously focus on environmental barriers *and* work to gain an understanding the personal experience of using AT (Barnes, 2003). Orfanakos (2006) provides a personal account of how he reconciled the ontological differences between individualistic and social models as an orthotic user. In fact, situating AT use and meaning in the larger social and political context may be key to understanding how and why individuals choose to use or not use a particular AT device, a paramount issue in the AT field that remains unresolved (Seymour, 2005; Steel & Gray, 2009). Adopting an emancipatory approach to AT research would mean that the research produced serves to address the ways that society enables and/or disables individuals with disabilities who use the technology (Lupton & Seymour, 2000). Research that addresses individual impairments while addressing the environmental barriers can co-exist (Orfanakos, 2006) and embracing both views will be essential to the future of AT.

There is a further need to focus on empowering, rather than disempowering, individuals through AT research. Assistive technology researchers need to collaborate with disabled people as co-researchers, and provide them with opportunity to empower themselves through knowledge and capacity building. Researchers need to answer the questions that are meaningful to the disabled community, enable disabled people to create the research agenda, and simultaneously support efforts to address oppressive environmental barriers. To do this requires a paradigm shift by many health care providers and researchers, who require further knowledge of the social model of



disability, need to reframe language in terms of AT provision, and must continue to expand their focus beyond individual needs to consider the AT users' interaction within society.

For those deeply engrained in the biomedical model, adopting the principles and perspectives of the social model of disability requires this paradigm shift. However, this shift can only occur when there is an acceptance that the biomedical model creates and perpetuates an oppressive situation for those with disabilities (Shakespeare & Watson, 2002). As AT service providers and researchers are generally educated and employed by institutions organized around a biomedical model framework, this challenge may be considerable.

Zarb (1992) challenges that researchers have a choice about how we will use our position: to challenge the existing social and material relations of research or to remain silent, and continue with the status quo. In reframing AT and the location of disability, we can ask the following types of questions: How can AT be used to address issues of marginalization and exclusion that prevent individuals from full societal participation? How can we create a societal shift where a diminished number of people need AT because there is a concomitant increase in inclusive design and environmental access? How can we promote environments that are accessible and inclusive to as many individuals as possible, reducing the limiting and oppressive practices of exclusion? These kinds of questions are novel within the AT field, and they will require innovation

and creativity in research, education, and service delivery. This challenge is one that many consumers, AT service providers, developers, and researchers are ready to accept.

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## Chapter 12: Knowledge Translation

A broad range of end-of-grant and integrated Knowledge Translation (KT) activities were integral aspects of this project; each KT activity was tailored to the specific knowledge user. KT activities directed toward the funding organization (Canadian Paraplegic Association, Manitoba, Inc.) include a report providing a summary of the findings and recommendations, a copy of the photo book developed in this project back to the funding organization, and the development of a publication for the organization's member publication *Paratracks*. A range of peer-review publications and presentations directed towards an academic audience are in progress, or have been completed.

The manuscript in Chapter 11 provided further direction for engaging individuals in AT research in meaningful, relevant, and empowering ways that will be pursued subsequent to this dissertation. This perspective has formed the foundation for many of the knowledge translation activities associated with this dissertation. The primary barriers to participation highlighted by participants in the interviews and focus groups that had potential policy implications were subject to further review and were subsequently interpreted in light of existing jurisdictional policy, codes, and information. A wide range of policy and program information from government and non-government agencies that provide educational, vocational, health, or other social supports or services to adult Manitobans with SCI were sought to inform this aspect of the study. Specifically, there was an attempt to gain an advanced understanding of the policy or general information related to the identified barrier and how the policy may have contributed to the perceived

barrier. Policy data were analyzed using the framework developed at the conclusion of this study (Appendix K). An article for *Paratracks*, the newsletter of the Canadian Paraplegic Association (Manitoba) is in preparation that describes the key community participation barriers and facilitators, and links related policy, and recommendations to each of these.

One finding of the study, *pseudo-accessibility*, was further examined in collaboration with a former study participant. This individual engaged as a co-researcher to develop and co-present one aspect of the study findings with the student researcher at a scientific conference in June 2011.

The current project represented in large part the knowledge creation aspect of the knowledge-to-action cycle (Canadian Institutes of Health Research (CIHR), 2008) whereas the findings from this project will be used as a catalyst towards the action cycle of the process. Additional follow-up KT activities are planned based on feedback from the focus groups and will be the subject of a future participatory research project that focuses on increasing societal awareness of community accessibility. The findings around the challenges of AT during winter months provided the impetus for the development of a new research team. These ongoing research activities are consistent with the student's desire to enter a cycle of research focused first on understanding, and then on addressing, issues related to the use of AT and the AT-environment interface.

### **Chapter 13: Limitations**

This study sought to gain an understanding of the self-perceived participation experiences of individuals with SCI, and to develop a theoretical rendering of this experience. Although there was an attempt to use theoretical sampling to gain this perspective, research participants self-selected involvement in the study. This likely resulted in primarily hearing from those who had successful participation experiences and active community involvement, while those who felt disempowered, or had negative experiences elected not to engage in the study. The sample size was small, and while the findings did not suggest age or gender related differences between participants, a larger sample size may elucidate potential differences. As all study participants were Caucasian, future studies should explore how people with diverse ethnic backgrounds view self-perceived participation. The lack of full theoretical sampling was addressed by focusing subsequent interviews on gaining more insight into developing categories. Data was collected over a limited period of time, and thus did not represent participation experiences across the disability trajectory of these participants.

Not all 19 participants completed the study. Fifteen participants completed a second interview; two participants decided not to take and/or share photographs, one participant experienced a health issue that precluded ongoing study involvement, and despite repeated contact attempts, one participant did not respond to further invitation to be involved. Eight participants attended the focus group and five engaged in follow-up telephone interviews (total of 13 contributing); two participants who contributed photos

declined involvement in the final member-checking aspect of the study. Thus, the perspective of all original 19 participants was not attained throughout the entire study.

Although aware of issues of reflexivity, the student was the interviewer, conducted the primary data analysis, and is an occupational therapist researcher with an interest in promoting an assistive technology-environment fit and in modifying environments to promote occupational engagement. Consequently, judgment around advocacy and the importance of it, environmental barriers, and negative social attitudes were found particularly hard to suppress. These biases were occasionally made evident in transcript review, for example by probing the participant to discuss what he or she might do about a perceived injustice. Discussion with the student's advisor and peers, detailed probing with participants who held differing views than those of the interviewer, extensive field notes, and repeated review of transcripts prior to subsequent interviews were used as methods to address issues that arose through the process of reflexivity. However, as a thesis represents the primary work of the student, full triangulation of findings and developing theory by a team of researchers was not used to the same extent that may be expected in subsequent qualitative studies where the student is a member of a research team.

## **Chapter 14: Conclusions and Recommendations**

The objective of this research was to develop a theoretical understanding of self-perceived participation, and the influences on participation, for individuals with SCI. In doing so, particular attention was paid to the role of AT in self-defined participation. Consistent with several recent qualitative studies on the self-perceived meaning of participation (Hammel et al., 2008; Van de Velde et al., 2010; Van de Ven et al., 2005), the current study findings supported the concept of self-perceived participation as different from societal-perceived participation. Study findings suggested that self-perceived participation was not defined by type or amount of activity engagement, but rather by the ways that people felt engaged with, and connected to, their lives, homes, and communities. Participants engaged in activities, relationships, and roles that allowed them to experience participation as defined by achieving a sense of accomplishment, autonomy, reciprocity, and inclusion. This study provides further support for inclusion of the self-perceived aspect in conceptual definitions of participation.

Individuals in this study accessed, developed, and used strategies that supported their ability to participate with the support of, and at times despite, social, physical, and institutional environmental factors. The grounded theory of self-perceived participation amongst individuals with SCI developed provides a framework for clinical application and future research. Rehabilitation professionals working with individuals after SCI can view their role in terms of enabling the individual to address the body-environment interface through supporting the development of strategies identified by participants in this study. As rehabilitation professionals begin to understand and accept the tenets of the

social model of disability and accept the wide-ranging influence the environment has on creating disabling conditions, they can use the power they hold as professionals in society to adopt a broader societal role. By working in collaboration with individuals with SCI, they can continue to address environmental barriers to participation, for example by advocating for improved community accessibility, promoting the development of respectful and transparent policy, and increasing societal awareness of environmental barriers to participation.

While this study contributed to the initial development of a theoretical framework for self-perceived participation for adults with SCI, research should be conducted to test the transferability and feasibility of the theory. For example, theoretical sampling in the current study led to the inclusion of several participants who had sustained their SCI in infancy. The experiences shared by these participants had nuances that provided some different dimensions from others who had sustained their injury as adults. Repeating this study with individuals who held different experiences of disability than of those who share the common experience of sudden SCI as an adult, would help clarify the role these different experiences play. Furthermore, the relationship proposed in the model between the intervening conditions and participation requires refinement, development, and testing.

Assistive technology, as a strategy for participation, holds unique meaning for individuals with SCI. As AT is used within a larger socio-cultural context, there are personal and environmental influences on meaning. The symbolic nature of AT, societal

reaction to device use and users, and cultural values aligned with western viewpoints influence the self-identify of an AT user and the meaning an individual places on AT use. The social, physical, climatic, architectural, and institutional (policy, funding and service provider) environments further influence the how, when, and what of AT use. Service providers have an important role in learning about all of these aspects as they relate to AT users, and a series of questions that service providers can use to examine these aspects was proposed. On-going research is necessary into the meaning of AT among AT users that takes into consideration the complex social, political, geographical and economical contexts that influence their lives.

A need to redefine AT beyond its role in promoting function and independence in light of study findings was identified in the course of this study. Thus, a new definition of AT was proposed; this definition acknowledges the importance of the environment and addresses how AT should be used to promote self-perceived participation. The proposed definition is in accordance with the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007), that identifies AT as an important means for inclusion and participation of persons with disabilities. The proposed AT definition requires future stakeholder consultation, refinement, and agreement.

The study findings highlighted the need and opportunity to address multiple environmental aspects to promote self-perceived participation amongst individuals with SCI who are AT users. Burbank and Martins (2009) describe how synergistic use of symbolic interactionism (and its focus at the micro or individual level) and critical



perspectives (with a macro or societal focus) can be a useful framework for addressing complex social phenomena. Indeed, the synergistic use of these perspectives was found to be useful in this study, beginning with an initial focus on self-perceived participation and the meaning of AT the participant formed in relationship with the environment. The individual perspective gained using symbolic interactionism as a foundation formed the bases for future examination of the issues raised at the larger societal or macro level with an opportunity to explore avenues for social change and action (Burbank & Martins).

Through exploration of the theoretical and empirical literature on how the social model of disability and emancipatory disability research has been used with respect to AT and AT users, it was concluded that emancipatory disability research methods have been underutilized in this area. Adopting a research focus that addresses how environmental barriers create disabling conditions is congruent with the findings of the study. The research questions that emerged from the conclusion of the manuscript in Chapter 11 are as follows: How can AT be used to address issues of marginalization and exclusion that prevent individuals from full societal participation? How can we create a societal shift where a diminished number of people need AT because there is a concomitant increase in inclusive design and environmental access? How can we promote environments that are accessible and inclusive to as many individuals as possible, reducing the limiting and oppressive practices of exclusion?

These research questions, and a commitment to the synergistic use of micro and macro perspectives, have provided the scaffolding for the next phase of the student's

research. Future research will focus on exploring methods of creating a better AT-environment fit, with the intent of supporting efforts of working towards development of a more inclusive society.

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## Appendix A: Study Recruitment

Organization	Method
Canadian Paraplegic Association	Individual letters sent to all eligible members through mailing list
University of Manitoba Disability Services	Personal contact; Poster posted in office
Winnipeg Regional Health Authority <ul style="list-style-type: none"> <li>• Seating clinic</li> <li>• Assistive Technology</li> <li>• SCI clinic (out-patient)</li> </ul>	Received WRHA impact approval; poster posted in clinics and information shared with clinicians
1010 Sinclair Housing	Information shared with resident support workers who were asked to share with potential participants
Private occupational therapy services (n=7)	Personal contact made with clinicians who were asked to share study information with clients as appropriate
Pan Am Clinic	Personal contact made with clinicians who were asked to share study information with clients as appropriate
Red River Community College Disability Services	Personal contact; Poster posted in office

Organization	Method
Manitoba Seating Interest Group	Personal contact made with clinicians who were asked to share study information with clients as appropriate
Society for Manitoban with Disabilities wheelchair services	Personal contact made with clinician – unable to share information with consumers as unable to filter list
FOKUS housing	Information shared with resident support workers who were asked to share with potential participants
Manitoba Society of Occupational Therapists	Recruitment ad/information on study published in bi-monthly newsletter
Wheelchair Sport Manitoba	Personal contact; poster posted in main office

## **Appendix B: Introductory Letter**



UNIVERSITY  
OF MANITOBA |

Faculty of Medicine  
School of Medical Rehabilitation

R106-711, McDermot Ave.  
Winnipeg, MB R3E 0T6  
Telephone (204) 789-3397  
Fax (204) 789-3927  
Department of Occupational Therapy  
Department of Physical Therapy  
Department of Respiratory Therapy

March 5, 2010

Hello,

My name is Jacquie Ripat and I am currently conducting a study on **Assistive Technology and Adults with Spinal Cord Injuries**. This study has received approval from the University of Manitoba Health Research Ethics Board, and has received funding from the 2009 Manitoba Spinal Cord Injury Research Committee. We have recently expanded our inclusion criteria to include adults ages 18-65.

A detailed information poster is also included, but a quick overview is as follows:

- Participants will be adult Manitobans with a spinal cord injury (complete or incomplete)
- He/she will have been a user of an assistive technology such as a manual or power wheelchair, crutches, or scooter for a minimum of one year.

Participants in the study will be involved in 2 individual interviews, approximately one month apart, one group interview, and will be asked to take photos of relevant community activities, supports and barriers for discussion at the second interview.

Participants will receive an honorarium for each of the 3 interviews, will be provided with a digital camera (including adaptations and set-up if necessary), and costs will be covered for one trip to take pictures in their community (e.g. costs associated with use of a roundtrip wheelchair accessible taxi or equivalent).

If you have any questions about this study, you can reach me at 204-789-3303 or by email at [ripatj@cc.umanitoba.ca](mailto:ripatj@cc.umanitoba.ca)

Sincerely,



Jacquie Ripat



[www.umanitoba.ca/medrehab](http://www.umanitoba.ca/medrehab)

## **Appendix C: Recruitment Poster**

### **Invitation to participate in a research study Assistive Technology and Adults with Spinal Cord Injuries**

My name is Jacquie Ripat, and I am a doctoral student in the Applied Health Sciences program at the University of Manitoba. As a part of my doctoral degree, I am completing a research study to develop an understanding of how assistive technology influences the ways that adults with spinal cord injuries (ages 18-65) participate in their communities and daily life. This study has been approved by the Health Research Ethics Board at the University of Manitoba. My advisor, Dr. Roberta Woodgate, will oversee the study.

Through this study, we hope to learn about barriers and supports that exist in the physical, social, and institutional environments for adult Manitobans with spinal cord injuries. Specifically, we will gain an understanding of how the assistive technology devices and services lend support to, or create barriers, to participation and provide suggestions to improve these processes. We will explore how policies and programs facilitate and/or impede adult Manitobans with spinal cord injuries. Ultimately, through this research, we are seeking to understand the participation experiences of adult Manitobans with spinal cord injuries in order to promote their ability to participate in all desired aspects of their lives.

I am inviting adult Manitobans, who are users of a minimum of one assistive technology device (such as a wheelchair) as a major augmentation or replacement of function, and who are willing and able to discuss their perspectives on their assistive technology use and how it influences participation in their communities to be involved in this study. Individuals who agree to participate will be asked to take part in two individual interviews and one group interview. The individual interviews will be scheduled at a time and location of the participants choosing. The group interview will be held at the University of Manitoba at a time that is convenient for all participants. Participants will be provided with a camera to take pictures of aspects of their community that relate to how they participate in everyday life. Cameras will be modified or adapted to meet the unique needs of each user. These activities will be spread over the course of several months. Participants will receive an honorarium for their involvement and will keep the camera at the conclusion of the study. Thank you for considering participating in this study.

If you would like more information about this study, or are willing to participate in this study, please contact **Jacquie Ripat** by phone at (204) 789-3303 or by email at [ripatj@cc.umanitoba.ca](mailto:ripatj@cc.umanitoba.ca)



## Appendix D: Sociodemographic questionnaire

Date:

ID Number:

---

Gender:

Age/year of birth:

Type of spinal cord injury:

Time since injury:

Cause of injury:

Service agency involvement (past and current):

Family members (relationship, age, live with or apart):

Education:

Work status: (student/paid employment/unpaid employment/social assistance):

Community description:

Current assistive technology used, for each:

Type of AT	Features	Length of time used	Purchase/lease/loan	Acquired from	Functions used for	Frequency of use	Used independently /with assist

## Appendix E: Initial Interview Guide

Please tell me about yourself.

- How do you spend your day?
- What do you do in your free time?

Who are the important people in your life?

- Tell me about your family, how they treat you
- Tell me about your friends, how they treat you

What does participation mean to you?

- Tell me about some of the things you participate in/where you participate?
- Can you share with me some of the things you would like to participate in but feel you cannot?
- Can you provide an example of time that you felt you were participating?
- Can you provide an example of a time when you felt you were unable to participate?

Tell me about the (assistive technologies) you use.

- What kind of assistive technology do you use?
- Have you used AT in the past?
- How do you describe your (assistive technology)?
- Have you ever stopped using some assistive technology? Why?

Tell me what it is like to have (disability) and to use a (assistive technology device)?

- What are your experiences of using assistive technology?
- What is the greatest challenge of using this assistive technology?

- What are the positive aspects/consequences of using assistive technology?

Tell me about your community/the communities that you belong to:

- What are the environmental influences on assistive technology use/to an AT user?
- What barriers exist to using assistive technology?
- What facilitators exist to using assistive technology?

Tell me about your experiences in receiving your assistive technologies.

- What are the most helpful things that parents/teachers/siblings/peers/therapists have done to help you in the use of your assistive technology?
- Can you talk to me about your involvement in deciding what type of assistive technology to use? Your families'?
- What aspects of service delivery have been helpful?
- What aspects have not been helpful?

What recommendations for service providers to improve AT services?







What are your plans for the future?

- What do you want to do in the next year? Two years? Five years?

Conclusion

- Is there anything else you would like to talk about that we did not talk about?

## Appendix F: Photovoice Information Brochure

<div style="text-align: center; border-bottom: 1px solid black; padding-bottom: 5px;">  <h3 style="margin: 0;">Photovoice</h3> </div> <div style="padding: 5px;"> <p><b>What is Photovoice?</b> Photovoice is a <u>research data collection method</u> where participants use a camera to record aspects of their life from their point of view. In this study, you will be asked to take photographs of relevant individual, family, and community life experiences that illustrate the areas of life that are most important for you to participate in, the issues that affect your participation and the supports to your participation.</p> <p><b>Why are we using Photovoice?</b> Photovoice will allow you to create a visual representation of how assistive technology supports or limits your participation in daily life. This information <u>will be used</u> in the larger study to better understand the perspectives of adults with SCI and how they go about participating in life. This information <u>will be used</u> to improve AT services and to advocate for environments that promote participation.</p> <p><b>What will happen to my pictures?</b> The pictures you take belong to you. A researcher will work with you to download, <u>edit</u> and create captions for the pictures that you are willing to share in this research. We will ask you to <u>select</u> 10-15 photos that best represent your participation experiences. When you share the photos with the researchers, we will use them to encourage discussion of the things that are important to you. In the final focus group, all participants can share their photos and we will have a larger group discussion about things that we might want to address as a group.</p> <p><b>Problems with taking pictures?</b> If you experience any problems with the camera or taking <u>pictures</u> please contact one of the members of the research team. A member of the research team would also be available to accompany you to take pictures if you wish!</p> <ol style="list-style-type: none"> <li>1. Jacquié Ripat (researcher) Phone: 789-3303, email: <a href="mailto:ripatj@cc.umanitoba.ca">ripatj@cc.umanitoba.ca</a></li> <li>2. Haley Tencha (research coordinator) Phone: [REDACTED] email: [REDACTED]</li> </ol> <div style="text-align: right; margin-top: 10px;">  </div> </div>	<div style="text-align: center; border-bottom: 1px solid black; padding-bottom: 5px;">  <h3 style="margin: 0;">Photovoice</h3> </div> <div style="padding: 5px;"> <p style="text-align: center;"><b>Tips for Taking Pictures</b></p> <ol style="list-style-type: none"> <li>1. Think about the following questions: What does participation mean to you? What does it mean <u>to fully participate</u>? Try to show this in your picture.</li> <li>2. Take pictures of your <u>everyday</u> life.</li> <li>3. <u>Or</u> spend some time really looking around you. Take pictures of things you have never noticed before.</li> <li>4. Start with an opinion or idea. Create pictures to get your ideas <u>across</u>.</li> <li>5. Take pictures of all the things you are proud of or disappointed with in your community.</li> <li>6. Use your emotions as a cue. Consider what gives you an emotional response about where you live or how you live. Tell the story in a picture.</li> <li>7. Consider what is important to you. What is a big part of your life? Take pictures of objects, possessions, people, services, places.</li> </ol> <div style="text-align: center; margin: 10px 0;">  </div> <table border="1" style="width: 100%; border-collapse: collapse; margin: 0 auto;"> <thead> <tr style="background-color: #ffcc00;"> <th colspan="2" style="text-align: center; padding: 5px;">Photovoice Do's and Don't</th> </tr> <tr style="background-color: #fff9c4;"> <th style="width: 50%; padding: 5px;">Do be safe, take a friend</th> <th style="width: 50%; padding: 5px;">Don't take any risks</th> </tr> </thead> <tbody> <tr style="background-color: #fff9c4;"> <td style="padding: 5px;"> <b>Do</b> explain to people why you are taking pictures of them and obtain verbal permission                 </td> <td style="padding: 5px;"> <b>Don't</b> go anywhere you wouldn't normally go or do anything you wouldn't normally do <i>For example don't</i> take pictures of people who are "in private," such as through a window into their home.                 </td> </tr> <tr style="background-color: #fff9c4;"> <td style="padding: 5px;"> <b>Do</b> be especially careful when taking pictures of children. Obtain verbal permission from parents                 </td> <td style="padding: 5px;"> <b>Don't</b> forget that the goal is to connect with others and share ideas, not to upset people.                 </td> </tr> <tr style="background-color: #fff9c4;"> <td style="padding: 5px;"> <b>Do</b> ask yourself, "Would I mind if someone took a picture of me in this situation?"                 </td> <td style="padding: 5px;"> <b>You don't</b> need permission if people are too small to be recognizable                 </td> </tr> </tbody> </table> </div>	Photovoice Do's and Don't		Do be safe, take a friend	Don't take any risks	<b>Do</b> explain to people why you are taking pictures of them and obtain verbal permission	<b>Don't</b> go anywhere you wouldn't normally go or do anything you wouldn't normally do <i>For example don't</i> take pictures of people who are "in private," such as through a window into their home.	<b>Do</b> be especially careful when taking pictures of children. Obtain verbal permission from parents	<b>Don't</b> forget that the goal is to connect with others and share ideas, not to upset people.	<b>Do</b> ask yourself, "Would I mind if someone took a picture of me in this situation?"	<b>You don't</b> need permission if people are too small to be recognizable	<div style="text-align: center; border-bottom: 1px solid black; padding-bottom: 5px;">  <h3 style="margin: 0;">Further Info</h3> </div> <div style="padding: 5px;"> <p>Photovoice is an innovative way to gather information and evidence that can lead to improvement in public policy and healthcare. In a recent project, 10 individuals with spinal cord injuries used Photovoice to identify priority barriers in their community to educate the public and policy makers on the need for change. If you are interested in reading the article, the reference is below:</p> <p>Newman, S., Maurier, D., Jackson, A., Saxon, M., Jones, R. &amp; Reese, G. (2009). Gathering the Evidence: Photovoice as a tool for disability advocacy. <i>Community Perspective</i>, 139-144.</p> <p><b>*You can also view this interesting project on You-Tube! Available from: <a href="http://www.youtube.com/watch?v=nI4rrTYKmvE">http://www.youtube.com/watch?v=nI4rrTYKmvE</a>.</b></p> <p style="text-align: center; color: #ff0000; font-weight: bold; margin: 10px 0;">Happy Picture Taking!</p> <div style="text-align: center;">  </div> </div>
Photovoice Do's and Don't												
Do be safe, take a friend	Don't take any risks											
<b>Do</b> explain to people why you are taking pictures of them and obtain verbal permission	<b>Don't</b> go anywhere you wouldn't normally go or do anything you wouldn't normally do <i>For example don't</i> take pictures of people who are "in private," such as through a window into their home.											
<b>Do</b> be especially careful when taking pictures of children. Obtain verbal permission from parents	<b>Don't</b> forget that the goal is to connect with others and share ideas, not to upset people.											
<b>Do</b> ask yourself, "Would I mind if someone took a picture of me in this situation?"	<b>You don't</b> need permission if people are too small to be recognizable											

### Appendix G: Camera Modifications

Participant	Function	Camera	Access
1	C5/6 complete SCI	RJ Cooper switch-adapted Insignia camera with Dycem on camera body	Trigger switch for shutter
2	C4/5 incomplete SCI	Nikon Coolpix S220	Larger shutter switch
3	C4 complete SCI	RJ Cooper switch adapted Insignia camera	Mount on wheelchair bracket; power and shutter operated through EADL port on power wheelchair
4	C5/6/7 incomplete SCI	Canon SD1400	Customized handgrip threaded onto mount Larger shutter switch (non-recessed)
5	L5/S1 incomplete SCI	Sony Cybershot DSCW310	Standard
6	Paraplegia	Sony Cybershot DSCW310	Standard
7	L3 incomplete SCI	Sony Cybershot DSCW310	Standard
8	C6/C7 complete SCI	RJ Cooper switch-adapted Insignia camera	Customized car window mount; Spec switch x2

Participant	Function	Camera	Access
9	Quadriplegia - Incomplete	Canon PowerShot SD1200	Standard - opted for family member to take pictures
10	Paraplegic - Incomplete	Sony Cybershot DSCW310	Standard
11	Quadriplegia - Incomp	Canon Powershot A490	Larger shutter switch
12	C6/C7 complete SCI	RJ Cooper switch-adapted Insignia camera	Microlight switches x 2
13	Paraplegia	Panasonic Lumix DMC FH1	Standard
14	Paraplegia	Panasonic Lumix DMC FH1	Standard
15	Paraplegia	Canon Powershot SD1200	Standard
16	Paraplegia	Canon Powershot A490	Standard
17	C7/T1 complete SCI	Canon Powershot A490	Larger shutter switch (non-recessed)
18	C6/C7 incomplete SCI	Insignia video camera	Standard
19	C6/C7 complete SCI	RJ Cooper switch-adapted Insignia camera	Trigger switches x 2 Gorillapod tripod

## Appendix H: Focus group outline

Welcome

Introductions

Participation and assistive technology

*This is how you have defined participation (share findings) Comments?  
Additions?*

View pictures of the barriers and supports to participation in the five categories

*What are the main issues ?*

*How do these photos represent your ability to participate or prevent participation?*

*Why is it this way?*

*This is how people described their AT (share findings). Comments?  
Additions?*

Purpose and use of photos

*Based on what you have seen and discussed; what would be your key messages/activities on issues of participation for individuals with spinal cord injuries?*

*How might we use these photos to educate others/promote social change? (e.g. YouTube video; photo display; iphoto book to share; presentation at events?)*

*What would you like to do with the photos?*

Final thoughts

*Is there anything anyone would like to add that they haven't yet had the opportunity to say?*



## **Appendix I: Photobook**



### **Photovoice Project**

#### **Participation, Assistive Technology, & Adults with Spinal Cord Injuries**

Fifteen individuals with spinal cord injuries living in Manitoba went out into their communities to document their participation experiences. Using digital cameras, they took pictures of facilitators and barriers to their everyday participation. The images were captioned by the photographers and grouped to capture their participation experiences.

## Appendix J: Informed Consent

### RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

**Title of Study:** Assistive Technology and Adults with Spinal Cord Injuries

Principal Investigator: Jacquie Ripat  
University of Manitoba  
R131-771 McDermot Avenue  
Winnipeg, Manitoba  
789-3303

Co- Investigators:	Dr. Roberta Woodgate Faculty of Nursing University of Manitoba	Dr. Emily Etcheverry School of Medical Rehabilitation University of Manitoba
	Dr. Joannie Halas Faculty of Kinesiology and Recreation Management University of Manitoba	Dr. Maria Medved Department of Psychology University of Manitoba

The principal investigator (Jacquie Ripat) is a doctoral student in the Applied Health Sciences Ph.D. program at the University of Manitoba. This study is being conducted by the principal investigator in partial fulfillment of the degree requirements for this doctoral program. Individuals listed as co-investigators are the student supervisor (Dr. Roberta Woodgate), internal thesis committee members (Dr. Etcheverry and Dr. Halas) and the external thesis committee member (Dr. Medved).

You are being asked to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends or family before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

#### **Purpose of Study**

The purpose of this study is to develop an understanding of how assistive technology (AT) influences the ways that adults with spinal cord injuries participate in

daily life, in order to promote opportunity for participation through the use of AT for adults with spinal cord injuries.

A total of 20 participants are anticipated to participate in this study.

**Study procedures**

Adult Manitobans with spinal cord injuries who are users of a minimum of one assistive technology and are able to engage in in-depth interviews will participate in this study. If you agree to participate in this study, you will be interviewed on two occasions at a location of your choice (e.g. your home, community or public location). Participation in the study will be as follows:

Activity	Length of activity	timeline
Individual interview 1	Up to two hours in length	Beginning of study
Camera access, mounting and set up	one hour per assessment session; may require more than one session depending complexity of adaptations	Scheduled within the week after interview 1
Take photos	Dictated by participant	After camera is set up
Meet with research assistant to edit and select photos	Up to two hours in length	After photos are taken
Individual interview 2	Up to two hours in length	Approximately one month after interview 1
Focus group	Up to two hours in length	Scheduled between one and six months after completing interview 2

At the first interview session, we will ask you questions like: What is like to use your assistive technology? How do you participate in your community using your assistive technology? At the end of the first interview, you will be asked if you are willing to take part in the next part of the project, called photovoice, where you will be asked to take pictures of relevant supports and barriers to your participation in the community. If you agree to the photovoice component, we will set up another time(s) to meet and determine whether we need to make any modifications (such as alternate switch access), or set up a mounting system, for a digital camera that we will give to you to take the pictures. A research assistant will meet with you after you take the pictures to help you to download onto our research computer, ask you to select the most relevant pictures to discuss at the next (second) interview, and work with you to edit the pictures (to

remove identifying features of individuals in the photos). You will be asked to participate in a second interview, where we will ask you to show us the pictures you took and talk about why you took them, what they mean and how they relate to your community participation experiences. After that, you will be invited to a focus group that we will hold with participants where we will share our findings, and ask you about how well they represent your experiences. We will audiotape the interviews and focus group and take notes to capture additional ideas not recorded by audiotape.

You can stop participating at any time. However, if you decide to stop participating in the study, we encourage you to talk to the study staff first.

### **Risks and Discomforts**

There are no known risks to you for participating in this study.

### **Benefits**

There may or may not be direct benefit to you from participating in this study. At the conclusion of the study, you will be able to keep the digital camera, modifications (if applicable) and mounting device (if applicable) that you received to take your photos. We hope the information learned from this study will help us better meet the assistive technology device and service needs of adults with spinal cord injuries and better understand how community participation is limited or facilitated for assistive technology users.

### **Costs**

All activities will be performed as part of this study, and are provided at no cost to you. The cost of up to three wheelchair accessible van trips will be covered for you (and attendant) if necessary – one round-trip to meet with a rehabilitation engineer to consult on camera modifications and mounting; one round trip within your community (up to 20 km radius from your home) to take photos; and one round-trip to attend the focus group. The cost of one digital camera, modifications, adaptations, and mounting will be provided at no cost to you.

### **Payment for participation**

You will be given \$20 for participation in each interview and participation in the focus group (maximum of \$60/participant).

### **Confidentiality**

Only the principal investigator (Jacquie Ripat) and her supervisor (Dr. Roberta Woodgate) will have access to the confidential data collected in this study. All data will be destroyed seven years after study completion. Your name will be changed to a pseudonym on all data collected as a part of this study. Information gathered in this

research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. If photos are used in a presentation or publication, faces and identifying features will be digitally altered to prevent recognition. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes. All records will be kept in a locked secure area and only those persons identified will have access to these records. If any of your research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the University of Manitoba.

### **Voluntary Participation/Withdrawal from the Study**

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. If the investigators feel that it is in your best interest to withdraw you from the study, they will remove you without your consent. We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study. You are not waiving any of your legal rights by signing this consent form nor releasing the investigators from their legal and professional responsibilities.

### **Questions**

You are free to ask any questions that you may have about your treatment and your rights as a research participant. If any questions come up during or after the study, contact Jacquie Ripat at 789-3303, or her supervisor, Dr. Roberta Woodgate at 474-8338. For questions about your rights as a research participant, you may contact the University of Manitoba, Bannatyne Campus Research Ethics Board Office at (204) 789-3389.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

### **Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this research study with Jacquie Ripat and/or the study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form

after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study    Yes  No

Participant signature \_\_\_\_\_ Date \_\_\_\_\_  
(day/month/year)

Participant printed name: \_\_\_\_\_

I, the undersigned, attest that the information in the Participant Information and Consent Form was accurately explained to and apparently understood by the participant or the participant's legally acceptable representative and that consent to participate in this study was freely given by the participant or the participant's legally acceptable representative.

Witness signature \_\_\_\_\_ Date \_\_\_\_\_  
(day/month/year)

Witness printed name: \_\_\_\_\_

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent

Printed Name: \_\_\_\_\_ Date \_\_\_\_\_  
(day/month/year)

Signature: \_\_\_\_\_

Role in the study: \_\_\_\_\_

## **Appendix K: Framework for Assessing Disability Related Policies**

Nathanael Sawatzky & Jacquie Ripat

The purpose of this framework is to be able to identify issues related to persons with disabilities and assess the effectiveness of government and organizational policies surrounding those issues. In doing so, it is hoped that any shortcomings these policies may have can be identified, and that possible solutions may be developed.

1. What is the issue at hand?
2. Are there any common concerns or problems related to the issue?
3. Is the issue specific to any organization or entity? (If yes, go to question 6)
4. Is there public policy related to this issue?
5. Does the public policy related to this issue address any concerns associated with it?
6. Is the policy pertaining to this issue well written? (Does it effectively address the issue? Does it set out actual goals, or does it just make vague statements? Were all stakeholders consulted? Are intended outcomes measurable?)
7. Are there problems with the implementation of the policy? (Does it have government support? Has it been clearly communicated to the stakeholders? Is it enforceable?)
8. Do other jurisdictions or organizations have policies which deal with these issues differently? If so, what are the differences?
9. If question #8 revealed differences in policy, which policies are perceived to be more effective?