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## Exploring How Factors Impact the Activities and Participation of Persons with Disability: Constructing a Model Through Grounded Theory

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### Abstract

This paper explores a conceptualization of how factors impact activities of daily living (ADL) and participation from the perspective of persons with disability. This study identified what, and how, factors perceived by participants affect their daily activities, to better inform reporting of scores obtained on measures of ADLs and participation such as the Barthel Index and the Participation Scale. Grounded theory methodology was used to conceptualize a model, employing semi-structured interviews guided by categories of the above measures. Eight themes emerged from 24 participants, resulting in conceptualization of the successful adaptation model, which demonstrates relationships amongst factors, activities, and participation. Health professionals can use this model to assist persons with disability achieve desired goals.

### Keywords

Disability, ICF Activities and Participation, and Grounded Theory

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# **Exploring How Factors Impact the Activities and Participation of Persons with Disability: Constructing a Model Through Grounded Theory**

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*This paper explores a conceptualization of how factors impact activities of daily living (ADL) and participation from the perspective of persons with disability. This study identified what, and how, factors perceived by participants affect their daily activities, to better inform reporting of scores obtained on measures of ADLs and participation such as the Barthel Index and the Participation Scale. Grounded theory methodology was used to conceptualize a model, employing semi-structured interviews guided by categories of the above measures. Eight themes emerged from 24 participants, resulting in conceptualization of the successful adaptation model, which demonstrates relationships amongst factors, activities, and participation. Health professionals can use this model to assist persons with disability achieve desired goals. Key Words: Disability, ICF Activities and Participation, and Grounded Theory*

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## **Introduction**

Activities and roles that people engage in are influenced by personal and environmental factors such as individual abilities and external resources. Two existing conceptual models in the literature indicate a general interaction between personal and environmental factors, and the activities and roles that individuals engage in. They include the International Classification of Functioning, Disability and Health (ICF) model (World Health Organization, 2001), and the human development model of the disability creation process (Fougeyrollas, Noreau, & Boschen, 2002), which itself arose out of the conceptual model of the handicap creation process (Fougeyrollas et al., 1998). All these models rather broadly illustrate interactions between environmental and personal factors and activities and participation, also known as “life habits” or roles.

The assessment of activities and participation has generally been value laden (DeJong & Hughes, 1982). In other words, many scales presume that the activities and roles included in the scoring system are important to all individuals. However, people have individual preferences, and the activities that are important to one person may not be important to another. What is required is a better understanding of what matters to persons with disability, who may be impacted by a variety of factors. Whiteneck (1996, p. 180) indicated that “success is in the eye of the beholder” and “subjective reality is every bit as important as objective reality.” We wanted to know what persons with disabilities themselves believe affect activities and roles that are important to them. Understanding those factors that have a large influence in their lives may help those with

new physical impairments, and those working with them to better implement steps necessary to optimize engagement in their chosen activities.

Since the 1970s, with the rise of the independent living movement, initially in California, Texas, and Massachusetts (Boschen & Gargaro, 1998), new approaches, including self-help and peer support, led to new processes of service delivery for people with disabilities. Health professionals recognized the importance of working together in collaboration with persons with disabilities towards their goals. Historically, the independent living movement led to increased awareness of the physical and social barriers in the environment and encouraged new research directions (Dunn, 1990).

DeJong and Hughes (1982) suggested that research should focus on determining the external, as well as internal, influences on independent living (Boschen & Gargaro, 1998). Other scholars have suggested that it would be interesting to analyze the relationship between environmental factors and activities/participation to understand how external factors impact function (Voorman & Dallmeijer, 2006). Included in environmental factors are all external physical and social elements that can either aid or obstruct achievement of personal goals, and may include “family support, geographical location, terrain, economic situation, political climate, educational opportunities, architectural accessibility, support services, and cultural values” (Nosek & Fuhrer, 1992, p. 8). One term frequently used in the literature is “community integration.” This term refers to aspects of being part of mainstream community and family life, living independently, assuming age, gender, and culturally appropriate roles and responsibilities, and contributing to society as a whole (Dijkers, 1998); it is a correlate of community participation.

In rehabilitation literature, describing interactions affecting the lives of people, many person-environment models have been put forth. Some of these can be found in textbooks (e.g., Christiansen & Baum, 1997). Because a goal of rehabilitation is to maximize a person’s abilities to engage in activities and roles of choice in life, an important part of rehabilitation is to understand what factors impact upon the activities and roles of persons with disability. In recent years, two prominent models have emerged to depict the interactions that exist between personal and environmental factors and the activities of people, within the home or in the community. They are the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) and the Disability Creation Process (Fougeyrollas et al., 2002). These models are the first to clearly propose interactions between such personal or environmental factors and activities of people, reflecting understanding that determinants of health are not solely related to the medical state of a person, but is related to biopsychosocial factors.

### **Research Questions**

This study was developed from a need to understand what really matters to persons with disabilities. The research questions were:

1. What are factors perceived by persons with mobility limitations that affect their activities and participation?
2. How do self-identified factors affect activities and participation of persons with mobility limitations?

## **Methodology**

Grounded theory methodology (Glaser, 1978, 1992, 1993; Glaser & Strauss, 1967; Walker & Myrick, 2006) was used to explore experiential knowledge of persons with disabilities after a period of rehabilitation and adjustment of at least one year of community living. This methodology allows researchers to gather data from participants, and then systematically develop theory as derived from the data (Dey, 1999). Concrete experiences of participants were explored through in-depth interviews of participants, probing how the factors they identified affected specific activities in their lives. Reflective observations of participants' physical abilities were also recorded by the primary author during the interviews. Data collection activities associated with the tradition of grounded theory were used (Creswell, 1998). The constructivist viewpoint employed held that reality is constructed by individuals, and that multiple realities exist.

Ethics approval was obtained from the Queen's University and Providence Continuing Care Centre (now Providence Care) Research Ethics Boards. All participants were provided with a letter of information, screened for eligibility (including completion of a cognitive screen), and signed a consent form in order to be eligible for participation. Anonymity of participants was assured in all publications, and confidentiality was maintained at every step after consent forms were signed.

### **Selection Criteria**

Individuals 16 years of age or older with relatively stable neurological or musculoskeletal impairments, namely spinal cord injury, acquired brain injury, muscular dystrophy, poliomyelitis, arthritis, and other musculoskeletal causes of mobility impairment were selectively recruited into the study by written or oral invitation from the primary author. Participants were first drawn from the primary author's patient population, then from those known to the primary author or colleagues. After this, advertising in the local newspaper was used. Only individuals who required mobility aids such as a wheelchair or walkers were enrolled. Efforts were made to include several individuals in each diagnostic grouping through purposive theoretical sampling methods. Participants were selected for breadth of impairment type and life circumstance. A range of participants were chosen, including participants with recent and long-standing disability, minimal impairment to dependency, younger and older adults, single and married, gainfully employed and not employed, high and low income, and rural and urban residence. Details of the interview process are described below, but participants were generally asked to identify any large factors impacting upon their activities. They were also asked to rank the top ten factors impacting their activities. Participants were recruited until no additional large factors were revealed. As suggested by authors familiar with grounded theory methodology (Creswell, 1998), we anticipated that 20-30 informants would be included. Recruitment would cease when no further factors were identified. Therefore, preliminary data analysis occurred after each interview. Excluded were persons with severe communication impairment, precluding participation in an interview. All participants passed a cognitive screen through the application of the Folstein Mini-Mental Status Examination (Folstein, Folstein, & McHugh, 1975) by the primary author.

## Participants

Diagnoses of participants included poliomyelitis, stroke, traumatic brain injury, arthritis, amputation, multiple sclerosis, spinal cord injury, muscular dystrophy, and “old age.” The age range was 20-93 years (average 63.5 years). The average age reflects the demographics of the community from which participants were drawn, being in the top five most popular retirement communities in Canada (Canadian Business Online, 2007). It also reflected the composition of the practice population of the primary author. There were nine males, and 15 females, perhaps reflecting the fact that females live longer in Canada, with a life expectancy of 82.6 years as compared to 72.8 for males (Statistics Canada, 2006), and that older persons have more disabilities. The total number of participants was 24; eight were married, eight single, and eight widowed. All were living in the community, either in single family dwelling (15), multiunit dwellings (six), or residential settings (three) in which meals and housekeeping were generally provided. A mix of residential settings existed in our study population; three participants lived in urban neighborhoods, 14 in residential suburban areas, and seven in rural settings. Participants in all settings reported availability of additional caregiver assistance. Caregivers of three participants were interviewed.

Educational level of participants ranged from primary school to post-graduate levels (most did some post-secondary studies). For the 21 participants who revealed their income brackets, based on current Canadian income tax brackets, distribution was as follows: Eleven were in the lowest income bracket, nine in the middle income bracket, and one was in the high income bracket. With respect to employment, two were employed full-time, two employed part-time, four were unemployed, one was a student, and the remainder were retired. Three participants had taken early retirement before the age of sixty because of their impairments. Of the unemployed participants, two had never sought employment, while two were actively seeking employment. These demographics seem consistent with literature that links disability with lower socioeconomic status (Minkler, Fuller-Thomson, & Gurainik 2006).

## Sample

*Figure 1.* Number of new important factors identified by successive participants, until saturation.

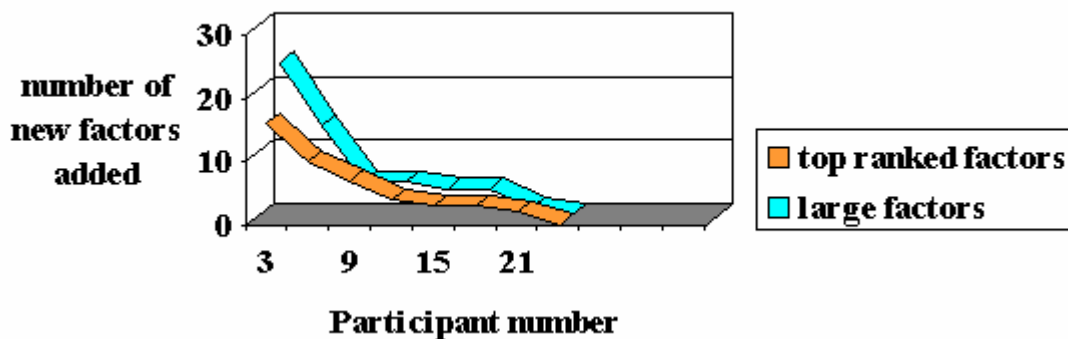


Figure 1 illustrates the number of factors identified as “large” in their effect on activities by successive participants and the point of saturation at which recruitment ceased. The graph clearly showed that most (80%) of the large factors were identified by the first nine participants. Saturation of factors identified as large, or within the top ten, was reached by the 24<sup>th</sup> participant, although new smaller factors continued to be identified by participants due to significant individual variation and uniqueness.

## **Interviews**

Participants were interviewed by the first author in person at mutually agreeable times and places. Immediately prior to interviews, demographic information was obtained. Interviews were recursive; in other words, issues were probed as they were mentioned by the participants. Open-ended questions were used to explore factors and experiences, beginning with an opening general question, “in the past year, or longer, what factors have affected your ability to do things in and outside the home?” Participants identified factors that in their experience affected their activities and participation.

In order that common activities and roles be explored in all participants, the semi-structured interviews incorporated two measures into the interview guide (see Appendix A); the Barthel Index (Mahoney & Barthel, 1965), a measure of activities of daily living and the Participation Scale (van Brakel et al., 2006), a measure of community participation. After the opening question was thoroughly explored, participants then answered questions for each domain of the above measures to ensure that factors were explored thoroughly. Activities explored included feeding, transferring, toileting, walking or moving around, dressing, being continent, finding work, working, helping others, visiting others, accessing the community, contributing to the household, taking part in recreational or social activities including festivals, eating with others, engaging in causes, level of respect received from within the family and community, and learning new things. For example, for feeding, the question asked would be along the lines of, “describe factors affecting your ability to feed yourself.”

Interviews lasted from between one to two and a half hours, with the majority lasting at least one and a half hours. Where feasible, triangulation was pursued through caregiver interviews. Interviews of caregivers took exactly the same format as those of participants, substituting the participant’s name instead of “you” for open questions.

## **Analysis of Data**

Participants were assigned identification numbers and audio-taped interviews were transcribed verbatim by a professional transcriber, checked for accuracy, and edited by the first author to ensure that the transcriptions reflected the actual interviews by simultaneously listening to the recordings while reading the transcriptions and making corrections where necessary. These transcriptions were entered into the data management program NVivo 7<sup>TM</sup> after each interview. The benefits of having interviews transcribed were a more detailed analysis and ability to group concepts together in participants’ own words. Transcriptions of caregiver interviews were added to the transcriptions of the relevant participants and analyzed in a similar fashion. There was no disagreement in

what caregivers reported as compared to what was reported by participants; rather, caregivers tended to provide additional information from slightly different perspectives. In general, their responses reflected those of the participants themselves, with the addition of only two additional factors.

Data were coded into categories or nodes by the primary author, and analyzed for themes and repeated patterns, through methods of constant comparison, as first described by Glaser and Strauss (1967). In coding, data are broken down, compared, and put in categories; it is a repetitious, inductive (in this study, proceeding from experiential data to conceptualization), and reductive (bringing back, or comparing back) process that organizes data for the construction of themes, descriptions, and theories (Walker & Myrick, 2006). Coding was conducted according to Glaser (1978) in two phases: substantive coding, consisting of open and selective coding, which generated categories, and theoretical coding, which developed the substantive codes into theory.

Open coding refers to categorizing the data “in every way possible” (Glaser, 1978, p. 56). Selective coding involves organizing the coding process around core categories or substantive codes. For example, open coding labeled as “doorways widened,” “pedestal sink installed,” and “stair-glide installed,” were collapsed into the more encompassing substantive code “home modifications” (see Table 1). Memoing was also employed throughout by the primary author, in notations of personal reflections on relationships between codes and categories, as well as observations as part of data analysis in order to provide a deeper personal awareness of any interaction between the primary author and the data analysis process. Glaser’s methods emphasize “what the subjects themselves are saying” (Glaser, 1992, p.50) in order to better guide the formation of a conceptualization.

Open coding was also performed independently by three other individuals (the second author, and two members of a qualitative research methodology group at Queen’s University) on four transcripts, in an effort to include analytical triangulation, or triangulation of the analysis by different coders. Coding between the primary author and these other individuals was comparable. Though triangulation may reinforce preconceptions, this was done at the very basic, sentence level, which showed good consistency in the codes used. The primary author derived higher order concepts from terms used by participants, and these were reviewed and discussed with two other investigators (the supervisor, and an advisor of the primary author) for the purpose of grouping of concepts. Examples of higher order concepts include cold, income, friends, rain, temperature, attitudes, orthotics, gait aids, power mobility devices, homecare supports, medical suppliers, and the like. From these were derived the main themes identified below. Categories, concepts, and proposed models were presented to a reference group of graduate students and faculty for feedback on the process derivation and presentation, rather than content, of the models to see if the methods, concepts, and models presented made sense to the reference group.

## **Results and Discussion**

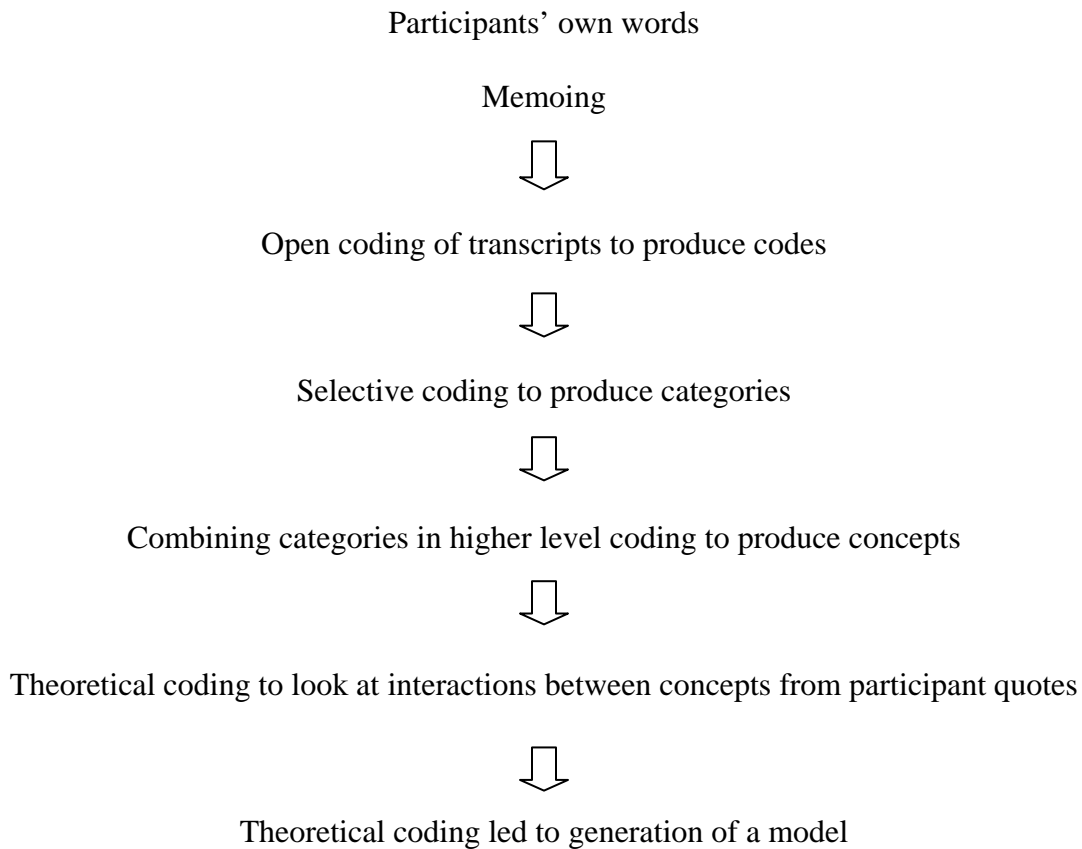
Participants were eager to share their experiential knowledge. Their words are in quotations in the text, and participant number is indicated with the designation “P-number.” As one participant summarized reasons for participating in the study, “I’ll tell



you about these things, because you can watch, but you don't live it" (P12). It is also possible that respondents represented a more outgoing and independent-minded group and may have higher overall participation levels and higher comfort levels when meeting others, possibly affecting responses to questions around the Participation Scale domain. "Are you comfortable meeting new people?" Responses such as, "I love meeting new people... I could talk to a door and get an answer" (P4), "I love people" (P8), and "I'm not hesitant in talking to people. I talk to them all the time" (P9) were typical.

### **Summary of Analytical Process**

To summarize the analysis of data, we present the following flow-chart of steps taken.



### **Memoing**

Memoing served to set the context of the content of the interviews. It served primarily to clarify the meaning of what was said in the interviews. If, for example, a participant gestured the size of a barrier, such as a one inch difference in height of floor surface, this would be recorded in a memo.

**Open coding**

Open coding led to 322 codes altogether, though 36 were related to domains on the outcome measures used to guide the interviews. They were removed in this tally so as not to add undue influence of the measurement scales to the coding content, since every participant was asked questions related to these domains. The domains were used for structure, and therefore, including them would artificially bias participants’ responses. Therefore, we were left with 286 codes that were generated by participants themselves that related to factors affecting activities and participation.

**Selective Coding**

Categories were produced by a selective coding process. Forty-three categories were reported by more than half of the participants, and all codes were compared against these. If they did not fit into these categories, additional categories were added.

**Higher Level Concepts**

Categories, as found in Table 1, were then grouped into higher level concepts. For example, cold or hot climate affected physical impairments, and physical accessibility.

**Theoretical Coding**

Finally, concepts were analyzed and placed into eight higher order broad themes. For example, the higher level concepts of past experiences, attitudes, and disability experiences were placed into the theme of experiences, while concepts of planning, improvising, and arrangements were fit into the overall theme of adapting to one’s life situation. The eight themes included the following:

1. Social context
2. Physical accessibility
3. Weather
4. Physical ability
5. Experiences
6. Individual attributes
7. Supports
8. Adapting

Table 1

*Themes and Categories*

<b>THEMES</b>	<b>CONCEPTS</b>	<b>CATEGORIES</b>
<b>Social context</b>	<b>atmosphere interaction social context stigma expectations attitudes</b>	self-consciousness, general population, schedules, apathy, balance, being single, counsel, country, crowds, encouragement, epidemic, fairness, fitting in, gender, high risk, interaction, normalcy, obligations,

		assistance, population density, predictability, prejudice, quality of life, relaxation, residence, smoking, social pressure, standing, teamwork, time, uncertainty, unmentioned, workplaces
<b>Physical accessibility</b>	<b>Barrier</b>	space, parking, home setup, outdoor access, and access of heritage buildings, housing, hotels, restaurants, terrain, workplaces, ramps
<b>Weather</b>	<b>climatic conditions</b>	winter (ice, snow), cold, rain, heat, humidity
<b>Physical ability</b>	<b>limitation abilities</b>	<b>a) Impairments:</b> safety concern, changes, complications, concentration, discomfort, effort, energy, energy expenditure, fatigue, health, high risk, infection, injury, level of consciousness, loss of function, memory and thinking, muscle, pain, posture, progressive condition, sleep, slowness, stamina, strain, thinking, variability, weight
	<b>treatments</b>	<b>b) Management:</b> includes beneficial medications, beneficial procedure, breathing equipment, course, distraction, emergency, hydration, medical suppliers, protection of body, rehabilitation team, remedy, side effects, surgery, ventilator, diet, nutrition
<b>Experiences</b>	<b>disability experiences previous experiences</b>	aging, effort, time, consequences, frustration, self-consciousness, reaction, achievements, alumni, annoyances, barrier, constraints, boredom, burden, childhood considerations, comfort, compromise, consequences, contemporary, demoralizing, disappointment, dependency, difficulty, embarrassment, falls, fear, fulfillment, grief, guilt, inconsideration, living alone, loss, mishap, misinformation, mood, not ready, regret, role model, stress, teasing, thankfulness, unease, unexpected benefits, unfamiliarity, widowhood, worth
<b>Individual attributes</b>	<b>personality role</b>	choices, dreams and desires, interests, self-advocacy, assistance, preferences, beliefs, confidence, consideration, curiosity, determination, effecting change, empathy, enjoyment, entitlement, facilitating, faith, freedom, generosity, giving back, global effort, helping others, humour, identity, initiative, maturity, motivation, persistence, principle, priorities, procrastination, religion, responsibility, sacrifice, self-expression, self-sufficiency, social consciousness,

		spirituality, spontaneity, susceptibility, teaching, unacceptable, vigilance, worth, certification, educational resources, knowledge, staying current, independence
<b>Supports</b>	<b>organizational systems</b> <b>transportation</b> <b>relationships</b> <b>support devices</b> <b>income</b>	services, arrangements, delivery, efficiency, legislation, mail, regulations, rentals car, bus, distance, rest spots, train family, spouse, helpful contacts, communication, closeness in relationship, keeping in touch, friendships, neighbours, understanding, church, club, peer group, adaptive equipment, computers, assistive technology, appliances, brace, custom made, devising and designing, incontinence pads, machinery, portability, repair, specifications, splints, supplies, telecommunications, benefits, insurance, pensions, caution, cost, expenses, funding opportunity, hiring
<b>Adapting</b>	<b>coping strategy</b> <b>planning</b> <b>problem solving</b> <b>improvising</b>	technique, acceptance, arrangements, thankfulness, asking for help, arrangements, back-up plan, convenience, emergency preparedness, ergonomics, exercise, flexibility, future, devising and designing, modifications, pacing, prevention, prudence, safety concerns, clothing choices

The substantive coding steps were conducted without adherence to any particular model other than the use of terms provided in the framework of body structures and function, activities, and participation provided by the International Classification of Health, Disability, and Functioning (World Health Organization, 2001). One participant even offered these terms in the interview: “The personal factors are fatigue, and environmental factors are ice and snow and lack of accessible sidewalks” (P4). In the words of participants, “personal factors” included the themes of physical ability, experience, individual attributes, and adapting, while “environmental factors” included the concepts of social context, supports, accessibility, and weather.

After substantive coding, the data were examined for relationships and interactions among the themes and concepts, through theoretical coding elements such as examining memos, related themes, and field notes on observations. At this point, we describe relevant concepts and relationships, linking our findings to the literature.

Relationships amongst factors that we found for persons with mobility impairments are outlined below.

1. Social context colours experiences. This refers to interactions between setting and roles, social attitudes towards disability and aging, and the need to educate the able-bodied population
  - a. Gender and marital status affect activities
  - b. Inaccessibility is a common barrier, reflected in legislation
  - c. Weather affects accessibility and physical ability
2. Physical limitations require more effort, time, and flexibility for activities
  - a. Experiences may influence activities/participation

- b. Individual attributes may be influenced by previous experiences
  - c. Individual attributes influence activities and participation
  - d. Supports assist activities and participation
3. Organizational systems may be facilitators or barriers;
- a. Transportation is a form of access, and may be perceived as barriers or facilitators, depending on availability;
  - b. Relationships can support;
  - c. Devices usually facilitate activities;
  - d. Income facilitates other factors;
  - e. In adapting, one engages internal and external resources

### **Social Context Colours Experiences**

Setting may influence the types of activities one does. Size of cities or towns makes a difference. In large cities, “you minded your own business. You went to work, you came home, you had your small circle of friends...you didn’t say hello on the street” (P4). In the country, people drive more, and spend more time doing “reading...walking ...gardening” and “with your neighbours” (P22). Dijkers (1998, p. 8) felt that the type of abode one lives, whether it be “in a private home, an institution, or in one of the intermediary forms,” can tell you about one’s community integration. However, our findings did not support this. Sometimes community activities of a residential home occupant increase once a means of mobility such as a power wheelchair is obtained, suggesting that other factors besides living abode may contribute to community participation. However, in some cases, rules of retirement homes may not be the most conducive; spouses with differing care needs are not able to stay together in the same room. Regulations may be untenable for some people, who “move out,” not liking “the regimentation” (P22). Some loss of autonomy seems to be the norm in residential settings: “I don’t go where I want to go; I go where the bus takes us” (P22).

The home is more than just a physical abode. According to Reid, Angus, McKeever, and Miller, 1997 (2003, p. 187- 188), the home is “a psychosocial environment constructed through the activities conducted,” and “domestic physical and social circumstances have a greater influence on occupational performance than the ability or inability to perform a number of activities independently.”

Despite advances made in human rights and social awareness in our society, persons with mobility impairment still face bigotry and stigma: “You don’t exist if you’re in a wheelchair” (P24). When first meeting people, many participants encounter discomfort on the part of able-bodied persons: “I’ve got to deal with their stuff before we can just get on to the sociable...a lot of people don’t know where to stand in order to carry on a pleasant conversation so I’ve got to... teach them” (P5). Persons with mobility impairment may avert unpleasant experiences by modifying their activities, avoiding occasions, such as weddings, not wanting to be “in that limelight to be shunned” (P8). The theme of presumed cognitive impairment along with physical impairment is a recurring one: “He sees an old woman, and she can’t even walk properly, and so obviously her mind’s gone too” (P19). One person explained why she tries to arrive at social events before others.

People look at you totally different when they see you at a desk, and then see you in a wheelchair later, because they see that you've been normal...but if they see you in a wheelchair first, they're almost surprised that you have a job...I think they think of you as...having maybe mental disability too. (P13)

Persons with mobility impairments do not allow negative attitudes to influence their outlook. If they do not feel like expending energy to change negative attitudes, they simply terminate the interaction. However, they do encounter difficulties in completing basic education, finding employment, and socializing, as has been found by others (Stensman, 1994), despite the existence of a national constitution that clearly states that no person is to be discriminated because of disability (The Government of Canada, 1982). Persons with mobility impairment do not feel they should have to hide their disability, but feel "pre-judged before you ever get the opportunity" (P23). "Potential employers" are not "familiar enough with the abilities of people with disabilities" (P6). Having attendant care makes it even more difficult to find employment. "Nobody's going to hire somebody and pay two people" (caregiver of P10). People with mobility impairments feel more respected by others when they do "have a regular job" (P23). Facilitators and predictors of employment "productivity" that health professionals should be aware of include physical therapy, age at onset, Barthel score, education, and housing adaptations (Dunn, 1990).

For the most part, persons with mobility impairment encounter positive attitudes from people of "all ages, they're always willing to help" (P14). Yet, many find it difficult "to ASK for help" (P15), being conflicted between the need for assistance, and the wish to be independent. Thus, the line where helping ends and intrusion begins may be difficult to determine, as in the following range of responses to assistance: "Some of them will... push your wheelchair...they don't tell you and all of a sudden, you think you're out of control" (P17). "A lot of people will go ...WAY beyond what they need to do, which is a KIND of lack of respect" (P2). One's "ability to cope" (caregiver of P13), "self confidence" (P6), and one's own outlook influence interpersonal interactions: "If I went around looking like gloom and doom, they would literally go in the other direction... it has SOMETHING to do with YOUR attitude" (P4).

Social attitudes have been identified to affect community reintegration (Boschen, Tonack, & Gargaro, 2003; Dijkers, 1998). Positive attitudes can facilitate social participation, according to Noreau, Fougere, and Boschen (2002), who maintained that social environment has a crucial influence on quality of life (QOL), in which "the individual measures in relation to his or her needs and expectations" (Stensman, 1994, p. 417). Having a disability does not necessarily affect QOL, nor does impairment severity. According to Dijkers (1997, p. 829),

Provided social reactions, public policies and environmental barriers do not prevent the person from pursuing work, leisure, civic duties and other activities, the QOL of a person with spinal cord injury (SCI) can be very similar to that of the average non-disabled person. It even may be better.

Rather, factors such as “lack of family role and occupation” (Dijkers, 1997 p. 835), and social support, may affect QOL (Dijkers,; Wee & Schwarz, 2004).

### **Gender and Marital Status Affect Activities**

As in the able-bodied population, persons with mobility impairment reflect gender related differences in life expectancy and perceived differences in behaviour. Women seem to accept mobility aids more than men. Reid, Angus, McKeever, and Miller (2003, p. 189) reported gender associated activities, indicating that women, regardless of age and disability status, continue to assume most homemaking activities, and were particularly hampered in their roles by inaccessible public spaces such as day care centres, libraries, community centres, and local parks, which prevented full participation in their children’s activities.

Being single affects one’s activities. People who were widowed reported marked changes in their activities because of the change in social status. One participant explained,

There are an awful lot of people who are friendly with you when you are a couple... they like...that balance at their dinner tables.... Then quite suddenly, you’re a woman on your own, and you realize that certain of your friends are not nearly so friendly now. (P19)

Marital status influences living arrangements (Dunn, 1990), and along with gender is an important factors in distribution of resources and how life is experienced (Dyck, 1995).

### **Inaccessibility is a Common Barrier, Reflected in Legislation**

Much has been written about physical accessibility. Architectural barriers affect community reintegration (Dijkers, 1998). “Canada has got to be one of the most accessible” (P4) countries; improvements have occurred over the years. In the past, “we were more hidden...if you couldn’t get into a building, well I guess you just didn’t go” (P15). Government policies such as accessibility standards (Treasury Board of Canada Secretariat, 2006) reflect this effort.

Despite this, when it comes to removing physical access barriers in places such as universities, “there are still plenty of people who have an attitude problem, like ‘why do we have to BOTHER with this?’” (P2). Participation in classes at university may be affected because of access barriers. Steinberg, Iezzoni, Conill, and Stineman (2002) described accessibility issues that faculty members with physical disabilities contend with such as entering campus buildings through loading, being unable to access library stacks, getting stuck on ramps deep in snow, struggling with heavy doors, and being unable to locate accessible toilets. Ramps and automatic door openers are sometimes poorly maintained, and wheelchair access routes often not clearly marked. Our participants indicated that some institutions provide scooters for use across campuses, but faculty must schedule extra travel time.

Many persons with mobility impairments are aware of current legislation regarding accessibility and reported the benefits of legislation in the United States: “Accessibility down there is different with the ADA [Americans with Disabilities] act, so I’d bring a ton of ideas back” (P12). However, “one person’s definition of accessibility isn’t the same as another’s” (P6). Places may be accessible to some, but not to others. The greater the physical impairment, the greater the accessibility barriers one faces in a non-universally designed environment. People who usually use power wheelchairs or scooters often have to have manual wheelchairs available for use because of problems with accessibility for power mobility devices: “Somebody could lug me down the steps...I can’t get in there with the power chair” (P16). Parking is an access issue, with participants reporting “a real shortage of spaces” (P6), with people “using the reserved parking slots when they really don’t need to” (P9). Sometimes, parking spots are too far away.

Accessibility determines where people frequent: “Their church was wheelchair accessible... that was a huge factor in whether I attended or not” (P4). Many have difficulties determining ahead of time whether or not certain establishments are accessible.

like southern Negro, you get in the back door...they should at least say whether or not I can get in. I bought it [a coupon book] last year. ...I think I used 2 restaurants. (P17)

Difficulty negotiating outdoor terrain is common. “My hands will fall off” (P10). Rural roads often do not have sidewalks. Grades, road humps, and design of roadways and ramps are often barriers. Outdoor accessibility is also affected by weather conditions, as described below. Other considerations besides physical access of buildings are also important. “Sometimes you won’t go if it’s very busy...like Saturday afternoons” or “around the Christmas season, ‘cause they tend to pack everything in the aisles” (P23).

By far, the most important areas to access for persons with mobility impairment are within their own homes; accessible housing is highly valued. The phenomenon of being restricted to a certain area in one’s home is referred to as “environmental centralization” (Reid et al., 2003, p. 192). Home modifications are often completed, with beneficial outcomes: “I have patio doors...they have a flat sill... I can get out myself” (P9). Home accessibility also has safety implications: “I’ve got my own elevator... mentally it’s a big one to know that I can get out of the house if it’s burning down” (P21). Dunn (1990) found that persons with disabilities living in an accessible housing environment spent approximately double the amount of time outside their home than those with housing barriers. Because of limited accessible housing options, persons with disabilities are often hesitant to move out, as they may lose current services and supports that may have taken significant time to set up (Reid et al.). This was reflected by our participants.

Persons with mobility impairment find it difficult to access others’ homes, influencing where socializing occurs. “They come to me, or...we all meet...in a location where they know I have the freedom to move around just as much as they do” (P4). Reid et al. (2003) also reported that many persons with disability entertained in their homes because of access issues. One person insightfully described,



I never realized before what it means if you have a non-accessible house. It's a HUGE shutting out of the rest...of the disabled community, to say 'my house is not open to you.' I think the majority of people never really THINK about it (P2).

Poor accessibility often deters people from visiting friends. It is tragic that people report "all my families' houses would be inaccessible" (P9). Policy makers involved with setting building codes should take this into consideration.

### **Weather Affects Accessibility and Physical Ability**

Inclement weather affects accessibility, and many "don't get out very much at all" (P10) in winter. Mobility devices do not seem to have overcome this aspect of life and more work needs to be done in this regard. Power wheelchairs may "shut down;" manual wheelchairs are difficult to push, and are "very hard on the hands [when] tires cake up with snow [and] rims get ice on them." Available transportation options become particularly important when weather is a barrier. Weather seems to affect parking availability as well. "When it rains, you don't want to go to the mall because all the handicap parking spots are taken" (P23).

Weather can affect physical health. Some people find heat and humidity to cause debilitating fatigue and may seek air-conditioning. Others find it "harder to breathe" (P10) or difficult to manipulate objects with clammy hands. "I get asthma in winter...Several times over the winter, I cancelled evening plans" (P2). "The cold makes my hands seize up, and then I can't drive my chair..." (P10).

### **Physical Limitations Require More Effort, Time, and Flexibility for Activities**

Some common difficulties in our study population included fatigue, pain, and weakness. Fatigue and limited activity tolerance is common: "Everything takes twice as long" (P12). The greater the physical impairments, the greater the effort required. Energy conservation is a strategy utilized to cope with such limitations: "I'm very careful how I portion out my life, because I know if I do overdo it, I pay big time for it in the days to come" (P4). Persons with multiple sclerosis, in particular, reported unpredictable fluctuations in fatigue and may find medications helpful. Neurological impairments cause various difficulties with chewing, feeding oneself, moving around, sensation, and concentration. Pain affects ease of conducting activities, and may affect sleep. Ways to cope with discomfort are found: "You walk through the pain. It's like having cranky old joints in the car. You kind of keep on moving them and they get a bit easier" (P19). Pain is recognized as a barrier to good adjustment in persons with disability (Boschen et al., 2003; Stensman, 1994). Physical limitations may influence decisions around stopping work. "It got to the point where I realized, from one day to the next, I couldn't guarantee him that I would show up... The time had come" (P4).

Secondary health problems may occur. "I've got to get my weight down...the biggest muscles in my body were paralyzed so I wasn't getting the kind of activity that I used to" (P6). "Anyone who pushes the chair ends up getting shoulder and back

problems” (P12). We include this concept here because management of health conditions contributes to overall physical abilities. There exists a general lack of inexpensive facilities for persons with mobility impairment to exercise in, for health maintenance and preventive management. A range of treatments, some of which are life-sustaining, were reported as beneficial, from incontinence pads to medications. Many are unable to mobilize without necessary orthoses such as orthopedic shoes or braces. Physical ability determines what types of devices would help in completing activities. A more complete discussion of the impact of devices is found in a later section. Self-discipline is often required in effecting treatment.

Aging with a disability is a reality that persons with mobility must contend with. Energy decreases, as do other facilities such as memory. Constant modification of health management is required as one ages.

I’ve modified my exercise routine, which has reduced my back pain, which has improved my mobility...I’ve also modified my diet again...as I get older in time, I have to keep modifying things, just to stay where I was before.... (P23)

As partners of persons with mobility impairment age, they too often gain impairments, and there is a leveling of abilities. As one ages, one may not be able to see one’s aging friends as often. Our findings concur with those of Stensman (1994), who reported a loss of energy with increasing age. This declining ability comes with a sense of loss, but many are able to adapt: “I think I’m getting to the age now where I can say ‘I’m sorry’ and let it go at that” (P8).

### **Experiences May Influence Activities/Participation**

Past social context such as childhood trauma and abuse may impact current outlook: Negative effects on mood may cause one to “back off from...even the nicest phone call” (caregiver of P3). Another described the impact of having lived through war.

You only need to be bombed a few times and then you really start to think what your life’s worth and what you’re doing with it... you shared, you were good. (P19)

Current roles influence activities: “It’s a lot of sacrifices: financial, family life... because you have to train” (P12) described an athlete. Sometimes, the home is so comfortable that one has no desire to travel, given the “aggravation” (P6) of travel, while others have to travel for work.

### **Individual Attributes May be Influenced by Previous Disability Experiences**

Previous experiences may influence personal outlook, both positively, instilling “confidence” (P5), “I had to prove myself...maybe to myself... because I had a disability...so my children... my house had to be really clean” (P15) or negatively

instilling fear, “I’m afraid to try it...I had a very bad fall” (P11). They have insights into childhood experiences of disability.

By the time I was you know 9, 10, 11, I already knew the meaning of prejudice, I knew the meaning of injustice, I knew the meaning of discrimination, but I didn’t know that they were words like that...Inside I was hurting, and I didn’t know who to talk to. (P15)

In a study by Stensman (1994, p. 420), 14 of 17 persons reported positive aspects as a result of spinal cord injury, such as learning “what is important in life,” and reporting “positive personality change.”

Persons with mobility impairments believe that many accessibility barriers continue because able-bodied persons are not aware of them and engage in educational efforts for lay persons, as a result of their own disability experiences. They understand what life is like for persons with mobility impairment, and may “re-arrange things at work to make it easier for them... [being] aware of how difficult it is to get something done” (P13).

I really believe that people...that have the disabilities are the ones that have to go out there and do, because it’s very hard...for someone else to even know what the person with the disability is facing. ... How would the other people in the community have any idea whether the curb isn’t right, or whether the parking is available ...unless you’re actually experiencing that?...It was an awareness program. (P15)

Benefits of these collective efforts are clear, and some groups succeed in common goals such as effecting accessible housing for persons with disabilities in the community. However, organizers of groups often take on personal toll and may need reprieve.

### **Individual Attributes Influence Activities and Participation**

One’s personality and “determination to just keep going” (P4) appears to be a “HUGE” (P4) influence. However, some are reluctant to influence the activities of others: “I don’t wanna get there and have them not do something that they plan to do because I can’t go” (P13). Some are influenced by fear of mishaps, such as in solo travel, while for others, fear of future inability is motivational: “I’m really worried about the days when I’m not going to work.... I wanna get as much accomplished and have life as normal as possible ‘til I can’t do any more” (P13). “Self-efficacy” is a term used to describe a person’s belief in his ability to deal effectively with the environment (Bandura, 1989). Examples of self-motivation and positive attitudes abound. “I figure as long as I believe in myself that I will do whatever I aspire to” (P15); “my faith... affects everything I do... I’m determined if I’ve only got a short time to live, to live it well” (P19).

Many persons with mobility impairments see themselves as independent-minded. According to Rock (1988), “independence...should concern control and choice.” Aspects of independence include being able to make decisions, with “self-control” over one’s abilities, emotions, and behaviour and “environmental control” over human and physical

environmental factors (Nosek & Fuhrer, 1992). Nosek and Fuhrer described psychologically self-reliant individuals as, “emotionally stable, capable of functioning with little group support” (p. 8). However, in our study, participants claiming to be independent minded also recognized the value of peer support, and were often instrumental in organizing such groups. Persons with mobility impairments engage in principled decision making. “If a business isn’t accessible, I won’t even have someone go in and spend my money there” (P10). “I’d think twice about a building that... [has] stairs...I’ll be darned if I’ll be carried up” (P11). They find solutions to problems and advocate when required.

Naturally, personal interests determine chosen activities. Many send donations to charities as a form of helping others. “That’s one of the greatest pleasures of life. ... money in the bank, what’s that?” (P19). Some activities depend on aptitude and skill: “I can tell someone how to build one [computer] if they’re willing to do the physical work” (P10). “Education makes a big difference” (P2) in one’s ability to find meaningful work. One resource that many appreciate is “having the time to...sit and TALK to everybody” (P4).

### **Supports Assist Activities and Participation**

Physical ability alone does not determine activities and participation. Community minded persons with severe mobility impairments are able to achieve their desired levels (House, 1981) identified different types of support, instrumental and practical support, emotional support, and information/guidance support. In this section, we discuss five sources of support; organizational systems, including rehabilitation teams which provide instrumental, practical, and informational/guidance support; relationships, which provide emotional and practical support; transportation devices; and income, all of which provide practical support.

### **Organizational Systems May Be Facilitators or Barriers**

Organizational systems are relevant at two different levels; legislation exerts influence at the societal as well as personal level and local programs and regulations are relevant at the individual level. The positive effects of the Accessibility for Ontarians with Disability Act (The Government of Ontario, 2005, 2001) and the Americans with Disabilities Act (US Department of Justice, 1990) on access seem clear. “We’re going to see some significant changes in the next few years with the new ODA” (P6). The ADA does not allow discrimination against persons with disabilities in employment, and employers are required to provide reasonable accommodations (Jones, 1991) in areas of physical access, training procedures, assistive devices, modified work schedules, leave policies, and staff support (Steinberg et al., 2002). Limitations of accessibility legislation were acknowledged. Some suggested that administrators may “need to be pushed” (P6) to make changes. Legislation such as a ban on indoor smoking in public places can support the well-being of the population. “It’s opened up a lot of places for him” (caregiver of P10).

Some reported dissatisfaction with tax rules such as with the inability to claim taxi fare if one does not drive or own a vehicle, while others “can claim mileage” (P17).

Sometimes, employment assistance or disability insurance rules serve as disincentives: “I can’t look for contract work...Their rules are absolutely rigid... they would deduct penny for penny what I earned from what they would pay” (P5). People may try to find loopholes around existing rules. Regulations surrounding travel are also perceived as barriers: “I don’t think I could do it... be there 3 hours before a trip” (P11). Some prefer former to current policies. An example given was a former license plate system with handicap symbols compared with current use of disabled parking permits: “Wheelchair stickers can be abused” (caregiver of P3).

At a more individual level, organized programs and health professionals that work with persons with mobility impairment are often helpful. One participant found recreational therapy to open up possible adapted activities. Advocacy by rehabilitation physicians and other health professionals is appreciated.

We’ve been able...through our insurance, to contribute to the power lift on the chair. They’ve never done it before, but with the letters that I got, that’s very helpful. (P9)

Generally though, health professionals play a small role in the lives of persons with mobility impairments. Although rehabilitation services are felt to be beneficial, the report of Boschen et al. (2003) indicates inadequacy in the rehabilitation process, particularly with respect to supporting emotional recovery. They suggested that successful integration requires the provision of information regarding available services and resources in a timely manner, at multiple times and in multiple ways. They suggested that transitional and outpatient services should be expanded. Though rehabilitation professionals may influence community participation through functional restoration or environmental modification, other factors influencing societal participation and community reintegration may not be under their direct control (Whiteneck, Tate, & Charlifue, 1999).

Home support programs funded by government are crucial for quality of life and independence, for persons with mobility impairments, and their families. “Outreach has been phenomenal for me...through the government...it keeps my independence” (P4). Many feel that without this support they would “have to go to a nursing home” (P16) or “wouldn’t be alive” (P20). “The more people that you can keep...in the home, the happier they will be” (P21). Rules restrict access to such programs and some people must turn to friends or family for help. One participant’s tub lift supported independence in bathing, but this denied her access to home assistance. “You can’t get a homemaker unless you need personal care...I can bathe myself...but I never felt clean” (P8).

Attendant care funding programs support caregivers and allow persons with mobility impairment independence. It “is one of THE most important things in our family life ...we have a life, and HE has a life too” (caregiver of P10). Organized programs such as specialized camps teach people life skills and “how to live on their own” (caregiver of P10). Some participants pay for their own organized programs or private services. Service providers who come to the home are especially appreciated. Organized travel services make some trips enjoyable. “I’d never go on my own” (P19). Public services such as libraries are “VERY important. They do so many research things for me” (P20).

The postal service allows participants to communicate with others and send donations to charities.

### **Transportation is a Form of Access**

Difficulties in accessing public transportation are common. Lack of accessible transportation varies from city to city; it is a barrier to finding work for persons with mobility impairments. Accessible bus service may require reservations “2 weeks in advance” (P16), and hours are often unsuitable for employment purposes. People encounter differences in train and air travel, experiencing particular difficulties with air travel. “We did get abandoned...you have to wait... until everyone else goes...the attendant knew I needed help. ...It didn’t come” (P9). Potential solutions were suggested: “I think they should let the disabled person go out first and have a wheelchair at the top of the entrance way” (caregiver of P9). Purchasable transportation services such as taxis are appreciated; however, negative attitudes of taxi drivers are sometimes encountered: “There’s people that...won’t pick up wheelchair people” (P17).

The ultimate form of transportation appears to be private, adapted transportation. “I wanted a car very badly; I knew it meant freedom...I had to find someone to teach me how to drive a car...I know I needed hand controls” (P15). “If I get tired with being indoors...I can get in the car and go somewhere” (P19). Features such as sliding doors are helpful. Adapted vehicles allow people to continue living in locations of their choice. Suitable vehicles may be difficult to find: “I’ve always had a bench seat. The newer cars have...bucket seats and stick shift” (P15). Benefits of having one’s own vehicle include being able to “help others by lending” (P1) it to others. Lack of private transportation is a barrier for activities such as volunteering. When traveling, “if I don’t bring my own transportation, then FINDING transportation is really hard” (P24). People may secure rides from others. People generally prefer private transportation on special occasions rather than have their schedules dictated by availability of public wheelchair-accessible transportation.

I get together with friends at Christmas time, and weather being what it is, and the access bus being as unreliable as it is, ... they would rather put me in a manual wheelchair, and drive me over to wherever we’re going to.  
(P4)

### **Relationships Can Support**

Boschen et al. (2003) found that those who lived with at least one other person were more satisfied with their performance of daily activities compared with those living alone. DeJong and Hughes (1982) looked at ranking and weighting of living arrangement outcomes by members of an interagency council on independent living. In rank order, preferences in living situation were: living with a spouse or minor children, living alone, or living with friends/siblings; living with parents and spouse/children, or living with other relatives; and living in an institution, though results may be biased by their respondent pool. Many persons with mobility impairments feel supported by people they are close to: “Throughout our whole marriage...I had the sense of normalcy...we worked

as a team” (P15). The appreciation people have for their spouses is evident, indicating that without them, they may need to “make different arrangements for...everything” (P2). In a spousal relationship, one considers “what is best for both” (P9) in decision making. Flanagan (1982) reported that for men, the spouse was very important, while older women depended more on children and female friends. It is possible that this simply reflects the reality of different life expectancy for women and men, rather than a true difference in support preference. No such differences were obvious in the interviews of our married participants. Persons with mobility impairments feel they would be disadvantaged if seeking a spouse.

Children with disabilities appreciated their families and their parents stressed the importance of their own attitudes in encouraging their children’s independence. Elderly parents with disabilities appreciate assistance from their children, who often hold powers of attorney. However, parents may be reluctant to impose upon their children. “I don’t want them doing anything for me that I can do for myself, even if it means struggling with it” (P19). Extended family may not always be helpful: “Family attitudes can affect what you do and how you do things” (caregiver of P10).

Friendships were appreciated and recognized as important. Lost friendships were reported: “I lost a lot of friends when I was diagnosed...I found out who my true friends were, it was a hard one to swallow” (P4). Persons with mobility impairments may extricate themselves from certain friendships that “feel awkward... I have deliberately phased out...those friendships” (P14). For most, “people are...one of the reasons for living” (P14). Being in a wheelchair may actually facilitate meeting nice people: “I’m actually talking to MORE people” (P4). If family or friends provide help, their schedules need to be taken into account.

Coping and adapting to physical disability may involve learning from “people that are experiencing somewhat the same things...just to make choices” (P9). If one lives in a retirement residence, one is in a whole community of peers, who might look out for each other. Some feel strongly about the need for people to maintain friendships and acquaintances as they age, and for this reason suggest that retirement homes should not “be built unless there’s a nursing home that’s attached to it” (P21).

Persons with mobility impairments who were currently employed felt supported by their employers. Support may include providing scooters for longer distances on work property, providing closer parking spots, or allowing personal equipment such as wheelchairs to be stored at work. Some employers are clearly mentors and facilitators: “My boss...let me have that job for as long as I wanted” (P4). “The person that hired me had a disability...she knew...I had the capability. I didn’t have any self confidence back then. (P12). “He and his professors were prepared to help me in hospital...and he said ‘there’ll be a job for you’ (P19). Steinberg et al. (2002) urges those in leadership roles to encourage open communication with employees with disabilities, and be aware that persons with disability may fear requesting accommodations.

### **Devices Usually Facilitate Activities**

“Embodiment” is the term used for aspects of the person’s environment that are depended upon to complete activities (Reid et al., 2003). Many examples of embodiment are seen in persons with mobility impairments, in regards to wheelchairs, walkers,

transfer aids, ramps, environmental controls, and even attendant care aides if necessary. However, we also observe another phenomenon, which we termed “Embracement” of an object or device such as a wheelchair becoming considered an extension of oneself: “I just use the chair so often that I tend not to think of it... Without the wheelchair, I’d just be in bed all the time” (P10). “I made up a few wheelchair dances” (P24). “I go for a nice long ‘walk’” (P3, non-ambulatory). “I’d be lost without it. The wheelchair is literally my little world, because my little world goes with me” (P4).

When you step up on a curb...sometimes, you’re gonna misjudge that, and...stumble.... Same thing in a chair...the odd time, you misjudge ...and you end up flipping onto the pavement. (P12)

For some, the wheelchair is the “only means of transportation” (P16). Reid et al. (2003) also reported devices as representing freedom and extensions of themselves. Reid found that on average 11 assistive devices were used. She reported a constant need to negotiate and advocate for devices, to meet changing functional status. One participant described, “If I take my manual chair I can pretty much go anywhere.... I feel...more normal ...because it’s not as big so people don’t notice it as much. ...I love my power chair because I feel like I’m in control” (P24). Other devices such as scooters and golf carts also allow non-ambulatory people increased access. However, in the winter, these devices also go “into storage” as they don’t have sufficient “traction” (P6).

Even for those able to ambulate, “the wheelchair” may be “the biggest thing, because it gives... the most freedom.” Without wheelchairs, some ambulatory persons may be “restricted to being in the house” (P23). For others, the wheelchair allows easy carriage of objects or greater endurance for activities such as shopping. Not everyone becomes more independent with wheelchairs: Ambulatory persons with poor arm function experience decreased independence: “You have to wait for somebody to push you” (P21). Accessories for wheelchairs can be important. “The chairlift on my power chair has really taken...the stress off my arms completely” (P9). Reid et al. (2003, p.193) reported the wheelchair as being described as “my liberator, my sense of comfort.” Wheelchair specifications should be individualized with “proper seating and support” (P10).

Similar sentiments exist about gait aids such as walkers and canes: “Without the walker, I wouldn’t be able to get around... it’s part of me now” (P15). Without mobility aids many would “be in bed” (P21). Some people use gait aids for “a slight zone of protection” (P3). Others use different gait aids for different purposes; crutches for “rough terrain...increasing my range by about 3 times” (P23) as compared with canes and walkers when pain “is really acting up” (P23). Gait aids are often used in conjunction with lower extremity prostheses or orthoses for the lower extremities.

Grab bars, poles, and other fixed objects help by providing stability during activities such as toileting, as “something to hang onto” (P16). These devices, along with others such as raised toilet seats and bath or track lifts, may mean the difference between independence and dependency. Readily available conveniences available to the general population, such as electric razors, or kitchen appliances, may become necessities for some persons with disabilities: “Thank God for microwaves” (P4). “A dishwasher...very important; I’m always dropping things...cups and glasses” (P19). “That drafting chair...



[allows] the ability to do a whole variety of things ...within the kitchen” (P9). Computers, fast becoming a necessity in today’s world, are “a way to connect” (P5). Computers are more crucial to those with severe mobility impairments, and are felt essential to some, who use them for activities such as arranging travel, shopping, banking, storing information, and problem-solving: “Digital cameras are great. Take me a picture; throw it on the screen.” (P6), described a participant who was unable to access the furnace in the basement, but able to assist in solving practical problems with such technology. “My computer is...my life; everybody will tell you that...an extra, extra, extra large factor” (P24).

Similarly, telephone and other emergency communication systems are important, particularly for emergencies. Call alert systems are “like insurance. You don’t think you need it until it happens...One day, it might be supreme” (P14). The telephone helps maintain connections with friends who live in inaccessible homes. “I’d visit them in a phone conversation, or I’d make them come to me” (P24).

People “become VERY inventive” (P4), designing their own devices: “I drew...this tea trolley and had it made...I use that 90% of the time” (P14). “I designed a makeup tray” (P24). “I can [feed myself] with the help of...that tray...a neighbour did” (P9). “My other neighbour made me a driving stick out of an old piece of elm root...it’s great, ‘cause I can go around the yard” (P6).

Some drawbacks to having adaptive equipment relate to their bulk. “It makes traveling a bit more difficult... I generally bring most of my equipment with me” (P10). On the other hand, without equipment such as beds or mattresses, problems might arise: “If I couldn’t sleep, I wouldn’t function that well” (P13). Some equipment can be rented: “We’ve arranged to get...a hospital bed brought to the hotel room [but]...you have to rent it for a week...that’s the lowest they’ll go...through a medical supplier in the place...The planning’s a little complicated” (P10).

### **Income Facilitates Other Factors**

Many activities cost more money for persons with disabilities due to the need to arrange for equipment, climate control such as air conditioning, physical assistance, special transportation, or larger rooms. It seems ironic that people who experience a drop in income should bear increased financial burden: “I’m being more careful. I’m now on a disability pension and I’m a little more conscious” (P5). Some are fortunate to have insurance plans. Additional costs may deter one from visiting others: “You have to pay the person to wait for you” (P21). Costs may be a reason to move: “The house got too much for me, and it got very expensive when I had to hire everything for outside and inside” (P8). Yet, according to Dunn (1990), some costs, such as those of home modifications, are inexpensive relative to potential benefits. With approximately 56% of those needing home adaptations being home-owners, he suggested that municipalities consider building codes that ensure that new housing construction is accessible, and offering grants, loans, or reimbursements to persons with disability to modify existing units. There exist programs in Canada with such intent (Service Canada, 2007). Government programs and supportive relationships can reduce reliance on personal income, and funding of devices and other necessary supports helps people to complete their desired activities.

Sources of government funding include “Canada Pension disability. It gives a lot of people support” (P3) and provincial disability pensions such as Ontario Disability Support Program. Others have their own, or spousal pensions. “The private insurance one doesn’t go up every year; the CPP goes up every year” (P4). Income is a large factor in maintaining independent living: “Without my income I couldn’t stay, because I couldn’t expect...the government to provide it all...it costs me a lot of money to do anything” (P21). Availability of these programs may set some countries apart from others in their support of persons with disabilities (Wee, 2006). Income is a clear concern for the future for many participants: “The minute you go into old age pension, it goes down, so I have to take all of that into consideration... I plan years in advance” (P4). Whiteneck et al. (1999) suggested greater difficulties with economic self-sufficiency for those persons with SCI with greater injury severity, and over age 50.

### **In Adapting, One Engages Internal and External Resources**

The ability to adapt to changed and changing situations is crucial. “It’s a...forbidding territory...for the person who’s newly injured or someone who’s trying to reinvent themselves” (P6). “It’s a mental adjustment, but... you settle down and realize...you’re pretty lucky to do it at all” (P21).

The most immediate adaptations to new physical impairments generally involve developing new techniques such as in doing one’s hair or moving about. “When I’m coming down [stairs], I have to do it backwards” (P11). Adapting may involve finding new ways of completing tasks such as voiding on airplanes. “Use the male urinal...you can usually do it discreetly enough” (P12). Adapting takes trial, practise, and perseverance. “It took about 2 years to do a transfer into a van...confidence...balance, coordination, and strength” (P12).

Positive influences on the adaptation process reported in the literature include personality, ability to get help and support from spouses or friends, absence of pain, having work, previous experience, and time which “heals all wounds.” (Stensman, 1994, p. 420); Stensman found that the most difficult time after SCI was the first 7 months, and that “most persons succeed during the subsequent years in finding a new life” (p. 422). These respondents also lived in a socialistic society, with high financial security for persons with disabilities.

Many strategies are utilized in going about daily activities. “You wanna be able to do as much as possible with whatever abilities you still have” (P4). Persons with mobility impairments find more convenient ways of doing things, finding places with nearby parking, using delivery services, or shopping on-line. Improvisation is often required, at home, at work, and outdoors. “If you try, there’s a way. A lot of people...are able to work miracles at getting around a problem. (P14).

What I’m trying to do now is remember where the curb cuts are...once you throw ice and sand and snow on them, it’s gonna be more treacherous. So if I try to remember visually what’s out there, then I’d not be as likely to flip the chair. (P12)

Pacing is often required, and involves recognition of one's physical "limitations; I've learned that if you were going to over do it, you're going to pay for it the very next day". (P4)

Planning around all activities is key. "I have to plan carefully...how I can do it safely. I just don't take chances anymore, because if I fell and hurt myself...I'd lose muscles badly" (P9). "You have to think ahead... more than somebody else might" (P6). Participants planned for winter, and they planned extensively for trips.

Successful adaptation depends somewhat on individual attributes/experiences and ability to engage available supports. Adaptation is also a learning process; one learns to "integrate...a lot" (P15). "You learn to be very bold in asking for things" (caregiver of P10). When assessing others' ability to assist, one needs to be observant: "If people aren't comfortable, if they haven't... physically dealt with picking someone up or carrying them...I don't push" (P12).

Nosek and Fuhrer (1992, p. 8) reported that "being able to physically explore the environment and learn from it provides an experience base on which to develop the executive abilities necessary to succeed in our society." They also recognized the importance of individual attributes in adapting, "resources may abound, but if the person is unable to recognize, access, or manage them, they are of little use; ...individuals must elect to use equipment or assistance from another person." Bontje, Kinebanian, Josephsson, and Tamura (2004, p.141) described adaptation as "a twofold process in which society and disabled persons grow closer to one another." The person with disability engages in active exploration, modifies techniques, problem-solves, accepts, asserts oneself with family, uses home adaptations, mobility aids, and adaptive equipment for independence and enhanced functioning. Boschen et al. (2003) observed strategies of "retooling," "reframing," and "rearranging."

One also has to adapt to the attitudes of others in society. Personality affects adjustment to the social situations one faces. "If someone's got an attitude, no I don't have the time of day for that" (P12). Acceptance of reality seems integral to being able to adapt and adjust: "There's a lot of things I cannot do but I accept them.... I don't dwell on anything I have no control over" (P16). "You can't make these things problems. It would be nothing BUT a problem if you...just kept worrying about it" (P21). "I have no desire to prove anything to anybody anymore... proving... to oneself more than anything, that I can do that as well as anybody else" (P6). The following quotation describes someone who has adapted: "When my accident first happened, it was a much bigger deal, because you try to do everything you did before, but now my lifestyle's changed to accommodate it, so I don't even notice it" (P23). Passage of time helps. These reports concur with the findings of Whiteneck et al. (1999) who indicated greater difficulties with occupation, mobility, and physical independence in persons with SCI only one-two years post-injury, as compared with those with SCI for longer durations.

### **Factors Affecting Activities and Participation**

As demonstrated in the preceding sections, many factors affect activities and community participation of persons with disability. Personal factors such as physical ability, individual attributes, experiences, and adaptability were described, as were environmental factors, which include everything external to the person. In our population,

activities are generally affected by personal interests, abilities, necessity, accessibility, and adaptations, while roles result from interactions between personal attributes and societal context.

Environmental factors have been analyzed in a three-level classification system, from the personal to societal levels; microsystemic (e.g., job description), mesosystemic (e.g., factors necessary to do work, supports), and macrosystemic (e.g., access to labour market, legislation, universal design). Fougeyrollas et al. (2002, p. 3) argues that

if there were a clear internationally accepted conceptual model indicating that this disadvantage is caused not by the paralysis but by an environmental factor, insurers could be in a position to claim compensation from organizations responsible for such environmental barriers.

Factors affecting community integration have been identified in the literature to include personal choice (interest, motivation), economic circumstances, social, and architectural barriers (Dijkers, 1998). Participation is also influenced by formal rehabilitation services received, details of disability, personal attributes, family and social support, availability of housing, attendant care, transportation, and other characteristics of the environment (Boschen et al., 2003). Boschen et al. asked participants to indicate how important items were to them in 15 key life areas, and found that family relations and health were ranked the highest. Consistent with what we found, they reported greater income and greater time since injury onset as related to greater satisfaction with community integration. Health was an important predictor in their population, but was only one of many. Whiteneck et al. (1999) found that the combined factors of neurologic classification, age, years post injury, gender, ethnicity, education only explained 28% of variance in occupation, 9% of variance in social integration, and 18% of variance in economic self-sufficiency; therefore, these are inadequate predictors of community reintegration.

Facilitators reported by participants include supports such as provision of information related to disability: health stability; adequate income, including disability insurance programs and advocacy, self-help, and peer counselling and physical supports such as personal care attendants if necessary. Positive attitudes and support from family, friends, or colleagues (i.e., people who are accepting, understanding, emotionally supportive and encouraging) as well as familiar communities were appreciated. They reported tangible factors such as affordable, accessible housing, including assistance with home modifications and repairs; assistive devices and electronic technologies; personal or affordable, accessible public transportation; access to services; adapted work environments; and job opportunities and training. They also reported the importance of personality and personal motivation (Boschen, 1994; Boschen et al., 2003; Boschen & Gargaro, 1998; Dunn, 1990; McColl & Skinner, 1995; Noreau et al., 2002).

Through factor analysis, variables found to affect independent living included age-related data, health information, length since disability, income and education, gender and disability type, functional ability, attendant care, communication ability, physical activity, emergencies, locus of control, social support, self-reliance, accessibility of home, community, transportation, financial responsibility for residence, type of

residence, length at present residence, number of people living there, and assistance provided (Boschen, 1994). Noreau et al. (2002) found that those with new disability benefited more from counselling and employment services compared with those with disabilities of longer duration, and older persons with disability, who benefited more from public health and social programs.

Barriers or obstacles to community participation have been reported in the literature to include winter and summer; lack of job availability; uneven terrain, architectural barriers and lack of physical accessibility, including accessibility of friends' residences; time to carry out tasks; lack of available daycare; high cost of services/supplies/equipment; chronic pain and other health complications causing poorer health status; and negative attitudes of others (Boschen et al., 2003; Noreau et al., 2002). Boschen et al. reported variations in perceived influence of the environment depending on severity and completeness of SCI.

The majority of our participants appeared satisfied with their levels of activities and participation, although determining satisfaction levels was not the focus of our study. Others such as Flanagan (1982) did identify certain activities as "not well met," such as participation in activities associated with local and national government and public affairs, active recreation, learning, and education. However, there was no indication of the barriers to such activities in that population. If one understands the barriers to restricted activities, perhaps appropriate rectification or supports might be put into place.

We now discuss how we incorporated the concepts we derived through grounded theory methods according to Glaser (1978), namely, social context, accessibility, weather, physical ability, individual attributes, experiences, supports, and adapting, into a conceptual model.

### **Creating a Model**

We sought to depict the overarching theory developed through this grounded theory approach, in order to help people to better visualize and understand these conceptual relationships. From the descriptions and relationships provided by participants we obtain a complex picture of persons with mobility impairments having their own physical and individual attributes, perhaps influenced by prior experiences, optimizing and adapting to new conditions through the use of management strategies. The environmental factors they interact with include social context, physical accessibility, weather, and available supports, including organized programs and existing regulations, transportation services, relationships, sources of income, and devices (either through the assistance of health personnel, or through improvisation). They must be aware of such supports in order to assess and engage them as desired. They learn about such supports through peers or other lay persons, rehabilitation personnel, and through their own, or others' experiences.

### **Models**

Both the ICF model of functioning and disability (World Health Organization, 2001) and the human development model of the disability creation process (Fougeyrollas et al., 2002) operate at a high level, grouping environmental factors into one concept. The

ICF describes environmental and personal factors interacting with body functions and structures, activities, and participation. Health condition is considered separately, and also interacts with body functions and structure, activities, and participation. The Fougeyrollas model simply shows personal factors and environmental factors interacting with life habits, defined as daily activities or social roles valued by the person. They include health conditions within personal factors. Despite arguments of Fougeyrollas et al. against the ICF model, their model does not appear to add much to the one developed by the World Health Organization. They indicate that the ICF's recognition of environmental factors is ambiguous, but considering scenarios such as environmental factors leading to secondary impairments or causing disability as in societal attitudes towards a cultural group or persons of a particular gender (Wee, 2006) it appears that both models support these potential scenarios equally. These models are general, and do not delve much into components within personal and environmental factors.

Many person-environment models exist, and are presented by Law et al. (1997). The concept of "person" generally encompasses physical and mental states, needs, knowledge, beliefs, attitudes, capacities, learner preferences, and self-concept. The concept of "environment" includes the physical world, social, and cultural milieu.

Bronfenbrenner's (1977) Ecological Systems model presents concentric circles progressing from the micro system individual level, to the mesosystem family, work, or school level, to the exosystem social structural level, to the macro system societal institutional level. Factors described by our participants were of every level of this model. Davidson (1991) also used concentric circles to represent levels of the social environment. Another model is the Mandala of Health model by Hancock (1993). This model is similar in layout, but shows in more detail the components of individual attributes to include spirit, body, and mind. This model focuses on health as its main outcome. It explains determinants of health and is useful for advocacy in communities. However, it considers the individual as within a family unit, which seems to act as intermediary between person and environment: This relationship is not consistent with our findings, in which interactions occur more directly between the individual and the environment. Another useful model is the Person-Environment-Occupation model of Law et al. (1996), showing that ongoing development is a process in one's lifespan. This model shows activities as interacting with person and environment in a longitudinal fashion. Other models which try to detail the process of adaptation more also exist, showing various interactions between person and environment (Jackson & Schkade, 2001). Another type of model from which we drew in format is exemplified by the circular Occupational Performance Process model, describing various stages in the process of resolving issues (Fearing, Law, & Clark, 1997). Most importantly, we wanted to develop a model grounded in the data provided by our participants.

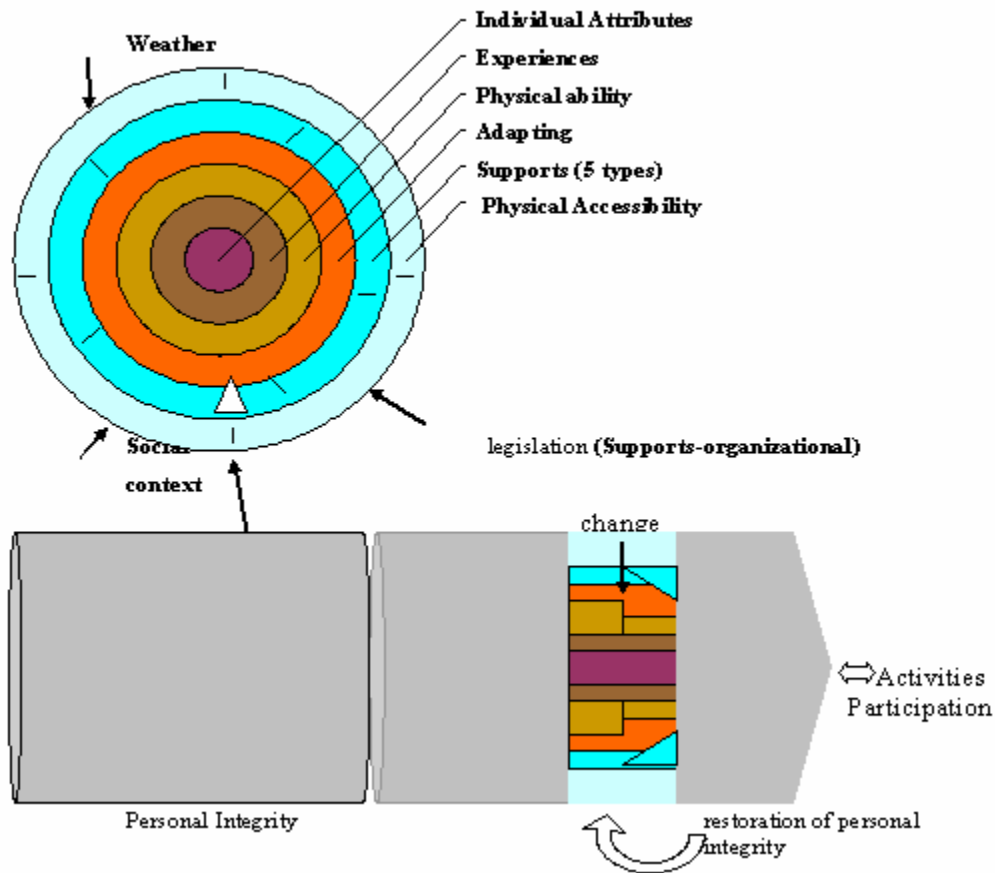
Given the large degree of inter-relatedness amongst the concepts obtained, we needed to consider a manner to depict such inter-relatedness of these concepts, leading to the tube metaphor shown in Figure 2. As an example of how concepts interrelate, someone with mobility impairments who is interested in attending a wedding in the heat of summer would be better able to do so if she has the motivation, available supports such as income, transportation, and devices, ability to overcome challenges of weather such as an air conditioned location, appropriate physical accessibility, and a supportive social context that is conducive to such participation. Interactions may occur between any

of these areas. Key in this is the personal factor; if the person decides not to attend, whether or not because of any other factor, this would be the deciding factor. Previous models do not allow for the multiple ways in which concepts may inter-relate with each other.

Figure 2.

*The successful adaptation model.*

Top: cross-sectional representation of tube; arrowhead points to personal factors; Bottom: sagittal cut of tube showing change (the example depicted is change in physical ability, and resulting adaptation through increasing supports) additional or progressive condition



In Figure 2, we present a model that includes the eight concepts identified through our grounded theory methods and how they inter-relate with each other. We combine elements of the above models, to illustrate the necessary steps in adaptation to change. We examined each level of conceptual inter-relationship, and determined that all of these concepts may interact with one or more of any of the other concepts, according to our data. The example depicted in the illustration is change in physical ability. However, the

change could be in any of the concepts. Amongst personal factors, changes may occur with time in the areas of individual attributes, physical ability, experiences, and adapting, while amongst environmental factors, changes may occur to social context, supports, physical accessibility, and most predictably, weather. Once again, the five categories of supports found were devices, transportation, income, relationships, and organizational or systemic supports. The latter is divided into two in the model, namely those systemic supports or programs that affect individual participants, and larger systemic supports such as legislation, which are more appropriately situated with other concepts that affect the larger community such as weather, social context, and physical accessibility. The proposed model assumes that one can adapt to changes one encounters, either by altering how one achieves completion of activities or by accepting one's limitations, and thus not attempting certain activities. This is supported by our findings in this population and setting. However, this assumption needs to be tested in other populations and settings.

At the core of the model are personal factors (indicated by arrowhead), from the most individual (in purple) at the innermost aspect, to concepts that affect and interact with these individual attributes (in various shades of brown and orange). We found personal factors to be very important for participation in our sample and have offered an understanding the various levels of personal factors that inter-relate, namely individual attributes at the core, affected by experience, physical ability, influencing one's adaptation, which is the interaction of the personal with environmental factors. Our sample was comprised of volunteers, and it is possible that the relative importance of personal factors may be biased because of this, volunteers may be more inherently motivated to participate in activities in general. Environmental factors are indicated in blue, including the supports that persons draw on when adapting and at the very outer aspect is the general environment of the society in which our participants live. Each conceptual "tube" should be considered as free to rotate upon other conceptual tubes and interactions may occur between any or all of these concepts in a given situation. For example, as physical impairment increases, accessibility barriers increase; when weather is bad, physical accessibility is worse, because of poor road and terrain conditions, and the social context of fewer parking spots being available due to people using more disabled parking spots; physical accessibility varies according to season, such as crowding at Christmas, indicating influence by social context; and experiences may affect individual attributes. Many other such relationships were described by our participants.

We combine activities and participation because of the difficulty in distinguishing them apart from each other as separate concepts. Activities/participation may in turn exert reciprocal effects on one or more factors. For example, community awareness activities of a person with disability may effect changes in attitudes of others, or physical accessibility of the community. Others, too, have grouped these two concepts (Jette, Haley, & Kooyoomjian, 2003; Voorman & Dallmeijer, 2006), which demonstrate particular overlap in some areas of life, such as economic and domestic life (Gandek, Sinclair, Jette, & Ware, 2007). Differentiating "activity" from "participation" remains a topic of investigation (Jette et al.).



## **Utility of Model**

Health care professionals working with persons with disabilities can use the above model to facilitate the abilities of their clients in achieving self-identified goals. Many rehabilitation teams are inter-professional teams, comprised of persons with disabilities and professionals from many different fields of expertise and concentration: Benefits of inter-professional teams (National League for Nursing, 1998) include the ability to intervene or contribute to all aspects of life that may affect activities and participation of persons with disabilities, which in our study included the areas of individual attributes, experiences, physical ability, adapting, accessibility, supports and organizational systems, weather, and social context.

With respect to individual attributes and adapting, our participants encouraged rehabilitation professionals to foster positive attitudes, facilitate additional education if required, and provide appropriate and relevant counselling to persons with mobility impairment. Self-advocacy, self-awareness, and problem solving abilities can be developed. Links to available resources and time-appropriate disability education can be provided. Everyone on the inter-professional team can contribute in these areas. Social workers, physicians, occupational therapists, and psychologists may all be able to support people in adjusting to disability experiences. We also saw how persons with disabilities themselves were change agents, providing such support to peers and removing environmental barriers for others. By educating the lay public, they also affected positive changes in social context, physical accessibility, and legislation. Inter-professional rehabilitation teams can and should contribute towards such efforts for there is much room for improvement.

One obvious task for rehabilitation professionals such as physiotherapists, nutritionists, nurses, occupational therapists, physicians, and pharmacists is to optimize physical status, and therefore physical ability. They could also facilitate supports such as transportation, care-giving assistance through organized programs, supplemental income, appropriate devices and home modifications, liaise with employers and educational institutions, and educate family members, friends, and others regarding how best to assist. One area in which the inter-professional team may need to consider more involvement is in dealing with the weather. This seems to be a significant barrier for many that cannot be altered. However, just as physical terrain can be modified, challenges around weather can be surmounted. Perhaps teams might consider bringing in biomechanical engineers to address the challenge of negotiating ice and snow. Education could be provided to business-owners, transit operators, and other administrators, regarding particular challenges related to weather. Surely we have the technology to be able to deal with this, rather than let persons with disability continue to curtail activities because of weather.

For many, rehabilitation intervention is brief and time-limited. What they rely on most are accessible homes, and relevant supports; assistive devices, income, relationships, transportation, and care-giving services. Therefore, rehabilitation professionals must try to ensure that each person with disability is equipped with necessary resources, ability, and knowledge for successful adaptation.

## Summary

This paper describes factors that affect activities of persons with disability, within the home, and in the community. It incorporates the personal experiences of mobility impaired persons in a North American setting through grounded theory methods into the Model of Successful Adaptation, depicting relationships amongst major themes that emerged from the qualitative data. It places personal factors at the core of the model, and for those who are motivated to maintain meaningful activities and participation, depicts the importance of adaptation in the face of change. It shows the inter-relatedness between personal and environmental factors, and that these interact in a two-way direction between activities and participation of individuals with mobility impairment.

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## Appendix A

### General Interview Guide

Questions to be used in conjunction with BI and P Scale: Consider placing in an outline form.

- In the past year, what factors have you noticed affect your activities inside and outside your home? or
- In the past year, what factors have you noticed affect your ability to
  - complete activities of daily living?
  - participate in your usual activities at home or in the community?
- Please identify the most important factor that would affect your activities, and rank order all factors reported.
- Please rate the impact of each factor (none, small, medium, large)

After this opening question is explored fully, proceed to,

- In the past year, what factors have you noticed affect your ability to (insert each domain activity or question from BI or P-scale)
- Please rate the impact on factors (none, small, medium, large)

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### Author Note

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