FACTORS AFFECTING ACTIVITIES AND PARTICIPATION IN PERSONS WITH DISABILITIES – INFORMING MODELS AND MEASURES

by

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A thesis submitted to the School of Rehabilitation Sciences
In conformity with the requirements for
the degree of Masters of Science

Queen’s University
Kingston, Ontario, Canada
(October, 2007)

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Abstract

Purpose- The World Health Organization describes ‘activities’ as what one does, and ‘participation’ as life situations or roles. This thesis explores and describes important influencers of activities and participation from the perspective of persons with disabilities. It also suggests how to include such information when reporting results of tools measuring activities and participation, so that health professionals working with persons with disabilities might collaborate and communicate more effectively with each other and the people they serve.

Method- The World Health Organization framework of the International Classification of Functioning, Disability and Health (ICF) was used. Participants with mobility problems living in the community with their disability for a least 1 year were involved in this mixed methods study to gain a broad understanding of how persons with disabilities perceive and experience factors that affect their general and specific activities and participation. Semi-structured interviews guided by categories contained in two standard measures, the Barthel Index (BI), and the Participation Scale (P-scale) were employed, and grounded theory methods were used. From their responses, relationships between important concepts were used to inform a theoretical model. Upon this framework, relevant important shared factors, derived through combining several methods, were incorporated into reporting tools.
**Results**- 24 participants identified 258 individual factors. Grounded theory analysis resulted in The Successful Adaptation Model, describing relationships amongst factors and activities and participation. For the BI, devices, home modifications, and treatments were most contributory. For the P-scale, personality, community and home accessibility, level of impairment, mobility aids, and transportation were among the most influential factors.

**Conclusion**- This study incorporates perspectives of persons with disability into the Successful Adaptation Model, describing factors affecting activities and participation and their interactions. It also suggests a method of reporting important factors in conjunction with standardized measures of activities and participation.
Co-Authorship

In this manuscript form of thesis, co-authors were involved in reviewing individual manuscripts for submission to peer-reviewed journals. Co-authorship of the three manuscripts included in this thesis is as follows:

1) Essential Mixed Methods - Integrating Methods in an Inquiry of Activities and Participation. Co-authors Rosemary Lysaght and Margo Paterson

2) Exploring How Factors Impact the Activities and Participation of Persons with Disability – Constructing a Model through Grounded Theory. Co-author Margo Paterson

3) Reporting of Factors affecting Activities and Participation in Persons with Disability in Rehabilitation Measures. Co-author Rosemary Lysaght

I was responsible for study conception, literature review, ensuring that all requirements to complete the study were met, participant recruitment and enrolment, interviews, arranging for transcriptions, analysis of data, and related oral presentations to date. My contribution to the contents of this manuscript includes all figures, tables, and new concepts, and is approximated at 98% of total contents, with input from my supervisor and co-authors.
Acknowledgements

I would like to acknowledge my participants for their courageous frankness and enthusiasm in sharing a part of their lives. Each one has succeeded in overcoming challenges of which others may have little awareness. As a group, they have made a difference, contributing to a more inclusive society, and it has been a privilege for me to learn more about their lives through this work.

I thank my supervisors, Sandra Olney, who was also my academic mentor at Queen’s University until her retirement, and Margo Paterson, who later joined as co-supervisor, and continued as supervisor after Dr. Olney’s retirement. They facilitated the entire process and helped me to maintain momentum in the completion of my thesis. Thanks for their support in my efforts to secure funding for this research project. Appreciation is also expressed to my co-authors and advisory committee members, Rosemary Lysaght and Margo Paterson, for their input into this work. I also thank all members of my oral defense examining committee for their valuable input.

I would like to express appreciation to the Queen’s University Inter-professional Patient-Centred Education Direction for a student stipend, and I am deeply grateful to the Clinical Teachers Association at Queen’s University and the Southeastern Ontario Academic Medical Association for funding this research.
I thank Providence Care – St. Mary’s of the Lake Hospital site and Queen’s University for their roles in facilitating this study, and the Department of Physical Medicine & Rehabilitation at Queen’s University for its support of my thesis work from the time that I joined the department in October of 2002.

I thank my family for its enduring support of my vocation and life decisions, and above all, I thank the One who guides my life’s journey.
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<th>Description</th>
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<tbody>
<tr>
<td>ADA</td>
<td>Americans with Disabilities Act</td>
</tr>
<tr>
<td>ADL(s)</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>Assn</td>
<td>Association</td>
</tr>
<tr>
<td>BI</td>
<td>Barthel Index</td>
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<tr>
<td>CIHI</td>
<td>The Canadian Institute for Health Information</td>
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<tr>
<td>cont</td>
<td>Continent</td>
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<tr>
<td>CPP</td>
<td>Canada Pension Plan</td>
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<tr>
<td>CTAQ</td>
<td>Clinical Teachers Association at Queen’s University</td>
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<tr>
<td>CV</td>
<td>Curriculum Vitae</td>
</tr>
<tr>
<td>DVA</td>
<td>Department of Veterans’ Affairs</td>
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<tr>
<td>eg.</td>
<td>For example</td>
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<tr>
<td>et al.</td>
<td>and others</td>
</tr>
<tr>
<td>etc.</td>
<td>et cetera (and other things)</td>
</tr>
<tr>
<td>FIM™</td>
<td>Functional Independence Measure</td>
</tr>
<tr>
<td>FRCPC</td>
<td>Fellow of the Royal College of Physicians and Surgeons</td>
</tr>
<tr>
<td>F/T</td>
<td>Full-time</td>
</tr>
<tr>
<td>I</td>
<td>Independent</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability, and Health</td>
</tr>
<tr>
<td>ID</td>
<td>Identification</td>
</tr>
<tr>
<td>i.e.</td>
<td><em>id est</em> (that is)</td>
</tr>
<tr>
<td>incont</td>
<td>Incontinent</td>
</tr>
<tr>
<td>km</td>
<td>Kilometres</td>
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maj  Major assistance
min  Minor assistance
MD  Doctor of Medicine
M.Sc.  Masters of Science
N/A  Not applicable
occ  Occasional
ODA  Ontarians with Disabilities Act
ODSP  Ontario Disability Support Program
PCCC  Providence Continuing Care Centre
PCCC-SMOL  Providence Continuing Care Centre – St. Mary’s of the Lake Hospital
P-scale  Participation Scale
P/T  Part-time
SEAMO  Southeastern Ontario Academic Medical Organization
SCI  Spinal cord injury
sup  supervision
tf  transfers
W/C  wheelchair
WHO  World Health Organization
Y/N  Yes/No
yr  Year
Chapter 1

General Introduction

Amongst health professionals who work with persons with disability, the benefits of teamwork, also known as interdisciplinary or inter-professional practice, are well-recognized. Many work in patient-centred interdisciplinary teams which develop coordinated approaches towards the attainment of desired goals of persons with disability. Though inter-professional teams have been in existence since the early 1900s, it was not until the 1970s that interdisciplinary teams training for health professional students was emphasized in some schools (National League for Nursing 1998). Good inter-professional practice involves a process of continual development, and in order to work effectively in teams, health professionals must increasingly understand where to focus their interventions. With this in mind, this study explored experiential knowledge of persons with disability in order to understand what contextual factors are felt to be important, and how they might impact activities and participation.

World-wide, one encounters many different environments, physically and culturally. Increasingly, rehabilitation professionals from many different nations are communicating with each other, and sharing outcomes from rehabilitation interventions. There is a push to assess quality of interventions, and to compare rehabilitation outcomes in different settings. I have been asked on several occasions to assess rehabilitation practices in other countries. Such a task is difficult without a clear understanding of context, because
persons with disability with particular impairments may not be equally able to engage in certain activities due to differing personal or environmental factors faced by people in different countries.

For example, when an individual sustains a spinal cord injury (SCI), there might be certain expectations of function. However, such expectations should be in keeping with the context within which the individual operates. At the present time, published charts on expected function after complete SCI indicate that these expected achievements depend upon proper equipment being available (Staas et al. 1993; Waters et al. 1996). In countries such as Denmark, wheelchair and transport aids are used by approximately 90% of individuals with SCI (Biering-Sorenson, 2004). In many areas of the world, such equipment is unavailable, and for many, it is unaffordable, rendering the published expectations of function invalid.

In the above example, assistive devices are seen as facilitatory factors. However, one rarely encounters discussions about appropriateness across environments (Bodine and Matthews 2005). Despite the recognition that assistive devices are helpful, there remains little outcome measurement research to assess how much such devices contribute to activities and participation (Cook 1995). Part of the problem is that a conceptual framework for the development of such measurement tools and measurement research in general has been elusive (Bodine and Matthews 2005). Therefore, this study aimed to
understand how factors inter-relate to provide a useful conceptual framework or model, based on realities experienced by persons with disabilities.

Rehabilitation professionals are leaders in functional assessment (Jette and Haley 2005), employing instruments to monitor clinically relevant outcomes across the continuum of care. These ‘outcome measures’ include ‘instruments of disability, function, activities of daily living, activity performance, advanced activities, physical performance, health, health status, quality of life, [and] health-related quality of life (p.339).’ Though over 100 instruments have been developed (McHorney 1997), there has been little standardization over the years (Fisher 1992). In fact, there is a growing concern that ‘there are now too many health measurement instruments (de Vet et al. 2003), given that many conditions may lead to common physical disabilities (Odding et al. 2001). As an example, balance difficulties may be due to impairments of visual, cardiovascular, vestibular, or other neurological causes.

A particular area of poor standardization is in the area of clinical reporting of different personal or environmental contextual factors that may exist between different individuals and different settings. Such reporting is virtually non-existent, or at best, only occasionally included in communications between rehabilitation professionals, regarding specific individuals, despite the widespread use of such measures for ‘benchmarking’ purposes, by national reporting systems such as The Canadian Institute for Health Information (CIHI), recognized as a world leader in health information systems (CIHI
A literature search of several electronic databases yielded no measures that require reporting of contextual factors, beyond a suggestion by authors of the Barthel Index (BI, Mahoney and Barthel 1965) to do so. Without an understanding of contextual factors, it may be difficult for an interdisciplinary inpatient rehabilitation team in downtown Toronto to understand the reasons behind any differences in data when comparing results of its rehabilitation efforts with those of a team from a similar sized rehabilitation unit in a rural area of Canada. To overcome this difficulty, CIHI tries to group similar centres together in comparing data. However, if contextual factors were reported in a standardized fashion when reporting outcome measures, perhaps more specific and useful information might be gained. The primary purpose of this work was to explore what contextual factors should be reported in standardized fashion, and propose a method of reporting them along with outcome measures.

Throughout this thesis, terms such as ‘impairment,’ ‘disability,’ ‘activities,’ ‘activities of daily living,’ and ‘participation’ are used according to the definitions of the International Classification of Functioning, Disability, and Health (ICF, WHO 2001, p. 10). ‘Impairments’ refer to problems in body function or structure while ‘disability’ is synonymous with ‘activity limitation,’ and refers to restrictions in executing activities. Whereas the ICF model implies that disabilities arise from impairments, in this thesis, ‘disability’ does not necessarily stem from impairments, as there may exist societal factors that limit the activities of people simply because of their demographic characteristics (Wee October 2006). An ‘activity’ is an action, while ‘participation’ is
involvement in a life situation (WHO 2001 p.123). ‘Activities of daily living’ are basic activities that one usually completes on a daily basis, such as feeding oneself, toileting, bathing, dressing, and grooming (McPeak 2000). Activities and participation are multiply determined by a range of personal and environmental factors, also referred to in this manuscript as contextual factors, as used in the ICF (p.8); because of this, condition-specific measures are thought to be flawed (Peat 2006). To aid exploration of important personal and environmental factors, constructs from more general, non-condition-specific, measures were considered for use in this study. In this manuscript, the term ‘population’ is defined as ‘a body of persons or individuals having a quality or characteristic in common’ (Merriam-Webster 2002).

Measures of activities of daily living (ADLs) such as the BI (Mahoney and Barthel 1965) and the Functional Independence Measure (FIM™ Hamilton et al. 1994) were developed to ease communication amongst health professionals regarding patient ability to conduct activities. In some rehabilitation fields, these two measures were found to be the most commonly used measures of disability (Sangha et al. 2005). However, these instruments do not require reporting of contextual factors that may influence scores; such factors could potentially include manner of performing particular tasks, mood, health status, and volition. Age may also be a potential factor influencing ADL function. For example, older persons with complete cervical cord injuries were found to do poorly in rehabilitation outcomes in one study, but ADL measures were not used (Alander et al. 1997). Though factors influencing ADL function in SCI may include home accessibility,
and assistive technology (Noreau et al. 2002), these factors are not usually reported with tools that measure ADLs. Naturally, scores would be lower in settings where equipment is not available, or when home accessibility is poor (Wee and Schwarz 2004). At least one other group has reported that clinical FIM™ data cannot be pooled or compared across countries (Lundgren-Nilsson 2005).

Both the BI and the FIM™ were considered for use in this study. The FIM™ includes social and cognitive components, which in published reports, have led to some discrepancies in scoring, while high patient-staff agreement was found on BI scores (Gauggel et al. 2004). The FIM™ was derived from several other indices, including the BI (Gosman-Hedstrom and Svensson, 2000). Also, no advantage in ability to determine severity of disability was found when comparing total FIM™ or motor FIM™ scores with BI scores (Van der Putten, 1999). Some feel the BI is preferable in neurological rehabilitation populations, and it has been found to be used more often than the FIM™, and in better quality trials (Hobart et al. 2001, Sangha et al. 2005). Additionally, unlike the FIM™, it is non-proprietary, and is more available for use in low and middle income countries. It has been also been compared with a ‘gold standard,’ and found to have good correlation, with an r value of 0.82 (p<0.001; Wellwood et al. 1995). The BI includes only physical components, which are more objectively measured and more easily incorporated into interview questions. For these reasons, and for practicality, the BI was the measure of ADLs chosen for this study. Because the original BI was found to be as
useful, or better, than a Modified BI (Wee and Schwarz 2004) in a study measuring activities and participation, the original form was employed in this study.

The Participation Scale is a newly developed tool based on the ICF, which provides a quantitative measure of individuals’ participation restrictions. Criterion and content validity, inter-rater reliability, and stability in time has been determined in Brazil, India, and Nepal, by the development team (The P-scale development team 2003). For external validity, the Delphi technique was used. Crohnbach’s $\alpha$ was 0.92, intra-tester stability 0.83, and inter-tester reliability 0.80. Details of its development can be found in the article by van Brakel et al., 2006. Its face validity was further documented in a comparative study involving Nepal and Canada (Wee and Schwarz 2004). In all, $\beta$ testing has been conducted in 14 independent centres. This scale was chosen for use in this study as a measure of participation because it was designed for use in low to middle income countries, and has also been found to be applicable in high-income settings, making it suitable for use in different global settings. Another desirable feature of the P-scale is that it allows persons with disability to determine the value of each domain for themselves, rather than attributing importance to specific activities, as do many other tools that are intended to measure participation. It is also non-proprietary and freely available for use in any setting. The BI and P-scale can be found in Appendix I.

The purpose of this study was to determine the main factors that influence function, and how these factors affect function, from the perspectives of individuals with mobility
related disability. The aim was to explore experiential knowledge (Higgs and Titchen 1995) after a period of rehabilitation and adjustment to community living. This study sought a better understanding of relationships between factors that affect activities and participation in persons with disabilities. The results of this study may guide the efforts of health professionals working with persons with disabilities, and be used to develop useful accompanying information for outcome measures such as the ones used in this study so that health professionals in different settings may communicate more effectively about the populations that they serve.

The research questions explored in this study were:

1) **What factors do persons with medically stable disability feel influence their ADL functioning and participation?**

2) **How are these identified factors perceived to affect activities of daily living and participation of persons with disability?**

3) **How can reporting of these factors be incorporated in a useful manner with standard measures?**

A mixed methods study was conducted, with pragmatic assumptions. Domains within measurement tools were used to guide part of the interviews, which consisted of both open- and closed-ended questions, as suggested by Creswell (2003). The perspective from which the study is conducted is a blend of constructivism, which recognizes that everyone experiences life differently, with different motivations and choices, and post-positivism, which believes that there are shared realities which may be understood, albeit
imperfectly. In other words, the perspective is that despite differences in individual experiences, there exist common factors that are barriers or facilitators, which if impacts are understood, may help health professionals maximize desired activities and participation of persons with disabilities. Such understanding may also help to improve the utility of reporting methods.

As a specialist in Physical Medicine and Rehabilitation, I approached this work from the physiatric perspective, with goals of minimizing impairments through diagnosis, prognosis, and management through an interdisciplinary approach, and maximizing abilities by working with persons with disabilities towards their desired goals, through interventions addressing aspects such as the environment, supports, resources, and educational needs. Actions might involve advocating on behalf of persons with disability in the arenas of education, workplaces, local communities, and income support, such as through insurance plans, legal procedures, and regulations concerning taxes. During data collection, I was cognizant of this role, and its potential impact on the interactions between participants and myself.

Data collection activities associated with the tradition of Grounded Theory were used (Creswell 1998, Charmaz 2005, Miles and Huberman 1994, Glaser and Strauss 1967). Both concrete experience and reflective observation were explored through interviews of participants. The majority of inquiry occurred through interviews. Questions about techniques and equipment used to optimize activities and participation were asked of
participants. Observations were also made and recorded. Qualitative inquiry used the interpretive paradigm to identify cause and effect relationships (Higgs 2001). Recurring themes were identified, specifically factors that affected activities of daily living (ADLs) and participation, along with their impact.

Details regarding methods are included in the three papers within this manuscript. The first paper (Chapter 2) provides an overview of the mixed methods used, placing this work within the existing body of literature regarding mixed methods. The second paper (Chapter 3) describes in greater detail the grounded theory methods used, and the relationships amongst factors as reported by our participants. The theoretical model derived through these grounded theory methods is also presented in that paper. The third and final paper (Chapter 4) details the quantitative methods used to rank important factors, including the use of data conversion (Caracelli and Greene 1993), and presents recommended templates for use in conjunction with the specific outcome measures used to guide this study, namely the Barthel Index (BI, Mahoney and Barthel 1965), and the Participation Scale (P-scale, van Brakel et al. 2006).

To summarize steps taken, a literature review was conducted, after which ethical approval was obtained through the Research Ethics Committees of Queen’s University, and Providence Care, formerly Providence Continuing Care Centre, in Kingston, Ontario, Canada (Appendix A). Funding for the project was obtained (Appendix B). Participants with a broad range of physical impairments living in the community for at least one year
were recruited (Appendices C-E). After being screened for eligibility, including successful completion of a cognitive screen (Appendix F), participants were provided with a letter of information, and signed consent forms (Appendix G). Anonymity was assured for publication purposes and confidentiality was maintained in all data collection processes after consent forms were signed. Interviews occurred at mutually agreeable times and places.

As is consistent with grounded theory methods, it was anticipated that 20-30 informants would be included until no additional large factors were revealed (Creswell 1998). Enrolment ceased at 24 participants. All participants completed a questionnaire and structured interview incorporating the Barthel Index and Participation Scale. Demographic information was also obtained. Appendix H shows the interview guide, domains of the measures used, and demographic information collected. Participants identified factors that affected their activities in and outside the home, were asked to rank the importance of these factors, and were scored individually on each of the two outcome measures. For three of the participants, triangulation through caregiver interviews was feasible and pursued. After the interviews, verification of responses through member checking was conducted by sending to participants a list of the factors they identified, and asking them to rank the top ten factors. Interviews were transcribed, and the contents of transcripts were analyzed with the assistance of NVivo 7, a data management program. Results from participants with related diagnoses were grouped and sub-analyzed in addition to analysis of the entire cohort. Data were analyzed for themes and
repeated patterns. The strongest associations in each domain were identified for the whole group of participants. Data were then incorporated into a theoretical model.

With the understanding gained through the conceptual foundation of the theoretical model, factors identified were rated for contributory strength through data conversion of self-reported rankings of factors, obtained during the interviews. Results obtained through data conversion and individual participants’ performances on outcome measures were analyzed and compared with results obtained through member checking and grounded theory methods. Through these different means of determining importance of factors, an overall ranking of influence by factors upon activities and participation was obtained. Ranking obtained through the various qualitative and quantitative methods were complementary. The overall ranking was then used to inform reporting mechanisms of contextual factors, to be used in conjunction with scores of the two outcome measures employed in this study.

In regards to format and organization, each of the three papers in this manuscript is presented in entirety, along with full references. Except for references, they are formatted according to targeted journals (The Journal of Mixed Methods Research for the paper in Chapter 2, The Qualitative Report for the paper in Chapter 3, and Disability and Rehabilitation for the paper in Chapter 4).
Chapter 2

Essential Mixed Methods - Integrating Methods in an Inquiry of Activities and Participation

Joy Wee, MD, FRCPC, Rosemary Lysaght, PhD, Margo Paterson, PhD

This article outlines a study in which qualitative and quantitative methods were integrated throughout the research process. Arguments are provided to support use of the term “mixed methods” for studies that integrate methods, and to further define and limit liberal use of this term. Such integration is best incorporated in the methodological planning stage. Studies that do not systematically integrate findings obtained through different methods to improve procedural and analytical decision making are better described as using “multiple methods.” Essential mixed methods is a term proposed for studies whose questions cannot be answered without mixed methodology.

Keywords: mixed methods research, exemplar, measures, research design, research paradigms, grounded theory

Introduction

Mixed methods are becoming increasingly respected in research, with a popular rationale being to enable a broader and deeper understanding of the issues at hand. Mixed methods allow researchers to explore the questions with appropriate designs rather than letting available methods limit the questions (Miller and Crabtree 2005). Sequential designs are
common, while sometimes the different methods are used concurrently (Morgan 1998, Nastasi et al. 2007). Published descriptions of many studies however, demonstrate little integration of the differing research traditions in the research conceptualization and execution. Often, initial rationales for employing mixed methods appear to be of secondary importance (Bryman 2007). What seems increasingly accepted is that mixed methods requires integration (Johnson et al. 2007). The value of integrating methods in more meaningful ways is becoming more commonly accepted in the research community. Integration can occur anywhere from design and conception, sampling and data collection, analysis, interpretation, to the write-up (Punch 1998; Brannen 1992; Sandelowski 2000).

There continues to be debate over terminology and definitions, with terms such as multimethods and mixed methods often being used interchangeably (Stange et al. 2006). Multiple methods is a term preferred by some when no integration is evident; others view “mixed methods” as separate from “mixed methodology,” the latter being a term that implies mixing of both paradigms and research approaches (Johnson et al. 2007). Even the term “paradigm” may be interpreted differently by different people (Morgan 2007). A good description of how paradigms and their associated research methodologies evolve is found in a recent textbook by Higgs, who discusses the notion that interest-driven knowledge should be free “from the constraints of single method science” (Higgs et al. 2007, p.35). Some purists argue that methodologies belong in paradigms, and that mixed methodologies can only be successful if they lie within the same paradigm (Giddings and
Grant 2007, Sale et al. 2002). Others maintain that understanding of complex phenomena requires collection of data from several perspectives (Clarke and Yaros 1988), and that it is erroneous to assume incompatibility of different theoretical paradigms (Cook and Reichardt 1979). Some feel that the main philosophy or approach behind mixed methods research is “pragmatism”, which tries to consider multiple viewpoints and perspectives (Johnstone 2004, Morgan 2007, Johnson et al. 2007). We refer to “mixed methods” as the term seems to be used most recently, to imply the mixing of any element, whether paradigm, ontology, methodology, or methods, as long as they are integrated.

In this paper, we present an example of a study that integrates methodologies throughout all phases of planning and implementation.

**Background to study**

The study question arose from a deficit in current instruments that measure activities and participation of persons with disabilities (Wee 2006), which provide us with scores, but no contextual information. For example, two individuals with similar physical limitations may score differently depending on whether or not they might have useful devices, or access to assistance. The International Classification of Functioning, Disability and Health (ICF, WHO 2001), developed through extensive consultation with international experts, gives us a framework of impairments, activities, and participation, as pertaining to disability: “Impairments are problems in body function or structure as a significant deviation or loss”; “Activity is the execution of a task or action by an individual”; and
“Participation is involvement in a life situation” (WHO 2001 p.10). An example of an impairment would be blindness, an activity, ability to bathe, and participation, attendance in school. ‘Activities of daily living’ (ADLs) are basic activities that one usually completes on a daily basis, such as feeding oneself, toileting, bathing, dressing, and grooming (McPeak 2000). The ICF states that “functioning and disability is conceived as a dynamic interaction between health conditions…and contextual factors…both personal and environmental factors” (WHO 2001, p.8). It details many types of body structures and function, and many existing environmental factors.

The developers of one instrument that measures ADLs, the Barthel Index (BI, Mahoney and Barthel 1965), initially advised that an explanation of special environmental requirements should accompany the tool. However, despite this instrument being validated and well accepted, reporting of such factors has not yet become standard practice. This mixed-methods study was designed to inform the development of accompanying contextual information for measures such as the BI, which to date, has not been developed into a readily accepted format for use when reporting outcome measure scores.

**Integration at conception**

A pragmatic problem requires a pragmatic solution. In trying to develop more practical and useful accompanying information for measurement tools, our **objective was to determine the main factors that influence function, from the perspectives of**
individuals with disability, for incorporation into existing measures of activities and participation. The aim was to explore experiential knowledge (Higgs 1995) of persons with disabilities, after a period of rehabilitation and initial adjustment to community living. Both concrete experience and reflective observation were explored through interviews with participants. We wished to answer the following two linked questions:

1) What factors do persons with medically stable disability feel influence their activities and participation? and

2) Which of these factors are of large importance, and should be incorporated into standard measurement tools?

A mixed methods study was planned, with pragmatic assumptions. Two widely accepted paradigms and approaches were used in this pragmatic inquiry. One employs qualitative inquiry from a post-modernist view (knowledge claims set within today’s world, and from the perspectives of people who experience a phenomenon, in this case, having a disability) within the interpretive/constructivist paradigm (Guba and Lincoln 1994, Higgs 2001, Denzin 2005). This view holds that everyone experiences life differently, and accordingly, each person with disability may experience different factors which impact upon activities and participation. The ontological perspective of the interpretive/constructivist paradigm used to explore factors is that reality is constructed by individuals, and that multiple realities exist. This approach was felt to be necessary to identify and understand the breadth of factors which may be involved. The other paradigm resides in the post-positivist view that there exist relative and incomplete truths
that can be uncovered through unbiased and controlled study (Denzin 2005). In this case, for the population being studied, this view pre-supposes that there exist common important factors that impact the activities and participation of the majority of persons with disability.

Greene et al. (1989) described five purposes for designing mixed methods studies: triangulation, complementarity, development, initiation, and expansion. The current study addressed two of these purposes: triangulation (seeking convergence and increasing validity of constructs), and complementarity (seeking clarification and increasing the interpretability and validity of constructs). Caracelli and Greene (1993) suggested that planning for data analysis needs to occur at the design stage. In our study, the plans for integration of analysis were made during early conceptualization of how to approach the study questions, and were modified only slightly based on participant responses, as described below.

**Integration of design**

We employed the constructivist “ground up” approach of reality as gleaned through grounded theory methods (Hutchinson 1993), to more fully inform measures that have been developed according to existing theories and frameworks. The first research question was approached by asking the following open question of participants: “*In the past year, what factors have you noticed affect your activities inside and outside your home?*” This question was explored fully with each participant before proceeding to
subsequent open questions. We believed that this broad question should be probed further by using the types of activities scored on these measures. Thus, we used the categories or domains covered by quantitative tools to extend the qualitative inquiry.

Validated measurement tools that were reasonably comprehensive, and applicable in different settings, were chosen for the current study. A measure of activities of daily living, the Barthel Index, and a measure of participation, the Participation Scale (P-scale, van Brakel et al. 2006), were employed, as these two constructs are generally measured with different instruments. An example of a category in the BI is feeding. For this category, the interview question was “what factors have you noticed affect your ability to feed yourself?” Questions were similarly modified for each domain employed in each of the two instruments. This strategy was designed to achieve maximal breadth in factor identification, available for textual analysis of verbatim translations, and responses could be compared with responses to the first open question alone. This is a variation of typology development strategy (Caracelli 1993), whereby categories developed from one set of data are applied to another.

The challenge of determining the relative importance of the factors described by participants needed to be addressed. A qualitative approach alone would not be sufficient to quantify magnitude of influence of each factor across the study population, though one might try to infer from experiences relayed in interviews how important each individual factor might be. Data conversion of descriptors to numbers would be employed. One of
the instruments chosen to guide the semi-structured interviews, the P-scale contains a built-in scoring system to rate personal importance of each activity. We used a similar rating system during the interviews. Every factor identified by a participant was rated by the participant as having no importance, or being of small, medium, or large importance in its impact on activities in general or the specific categorical activity being explored. Many participants added yet another level of response, that being “huge”, or “extra extra large”, which we added to the rating system. Thus, the measurement tools (BI and P-scale), which are quantitative, scaled-response instruments, were used to construct the interview guides, which consisted of both open- and closed-ended questions (Creswell 2003). Responses were in turn, converted to numbers according to importance.

Triangulation, first suggested by Campbell and Fiske in 1959, combines different measurement processes to obtain more persuasive evidence. If triangulation is thought to be beneficial in gathering evidence, it is important to incorporate triangulation strategy in the design phase of research. Various types of triangulation have been described elsewhere (Halcomb and Andrew 2005, Kimchi 1991, Dobratz 2006), including theory, person, time, space, data, methods, and multiple triangulation. We used the following methods of triangulation to verify the important factors impacting upon activities and participation: In addition to the interviews, each participant was also scored on each of the two instruments, as originally intended. This provided a quantitative measure that could be compared with observations, and analyzed with respect to possible influence of
factors identified by participants. Additional data and analytical triangulation methods were planned to add certainty and are described below.

The intent was to recruit participants until no additional themes were revealed. Recurring themes would be identified, specifically factors that affect activities of daily living (ADLs) and participation, and the importance of their impact. The activities associated with the tradition of Grounded Theory would be used (Creswell 1998, Charmaz 2005, Miles and Huberman 1994, Glaser and Strauss 1967) with particular emphasis on the methods described by Glaser. These are described in a flowchart in the data analysis section below. As researchers experienced in grounded theory methodology have indicated (Creswell 1998), it was anticipated that between 20 to 30 informants would be included.

**Integration in Sampling and Data collection**

Sampling was conducted according to grounded theory methods, which have been applied to both post-positivist and constructivist inquiry (Charmaz 2005). Various types of sampling techniques have been described (Teddlie and Fu 2007 p. 77) for mixed methods, including ‘probability sampling’ as used in quantitative studies, ‘purposive sampling’ as used to select units based for the specific purposes of answering a research question, and ‘convenience sampling’ that draws from easily accessible sources. In this study, purposive or theoretical sampling (Maxwell 1997 p. 87), in which particular
persons were deliberately selected for important information, was conducted. Theoretical sampling is used to develop emerging categories in grounded theory, with the aim of refining ideas, not to increase the size of the original sample (Charmaz 2000). It is pivotal in developing formal theory, and allows analysis of previous data to guide subsequent participant selection. Participant recruitment in grounded theory usually ceases when no further themes emerge with more interviews, also referred to a point at which ‘saturation’ has occurred (Morse 1995).

In this study, participants were chosen from two convenience populations within a geographic region – persons with disabilities under the care of the primary author, and volunteers with disabilities responding to advertisements in a local newspaper of a mid-sized city with a catchment population of approximately 160 000. Participants were selected through maximum variation sampling (Teddlie and Fu 2007) to maximize breadth of impairment severity and type, age, employment situation, marital status, income bracket, and living environment (rural, suburban, and urban), to achieve a sample representative of a broad group of persons with disabilities. In some instances where it was thought to be beneficial, caregivers and spouses were also interviewed. All were volunteers who provided informed consent. We determined that sample size in our study would be limited to the point of saturation of factors identified as “large.” In other words, participant recruitment ceased at 24 participants, when no new factors were identified by participants as having a large effect on activities and participation, even though occasional new small factors were reported by each additional participant. Observations
and field notes were kept, and journaling was employed. Participant scores, as scored with the instruments, and their interpretations, through published guidelines (Shah 1989, van Brakel 2006), were consistent with observations and what participants reported, and are described elsewhere (Wee and Lysaght 2007). Table 1 summarizes demographic characteristics of our participants.

Semi-structured interviews were audio-recorded and transcribed verbatim. Interviews were conducted in keeping with grounded theory purposes, starting out in an open manner, and progressing to more directive questioning (Wimpenny and Gass 2000). Behavioral observations were also made during the interview. All factors identified by each participant were listed. Member checking was conducted by mailing these lists to the individual participants, asking them to rank the top ten factors affecting their activities in general. The responses were returned by self-addressed, stamped envelopes. Through data conversion or quantifying (Caracelli 1993), each factor identified through categorical questions was ranked from 0 to 4, according to self-rated report (0 corresponding to no effect, 1 for small factor, 2 for medium effect, 3 for large effect, and 4 for extra large or huge effect). The purpose of this was to estimate the influence of each factor on scores.
Integration of Analysis

As is consistent with grounded theory methods (Hutchinson 1993), analysis occurred concurrently with data gathering. After each interview, preliminary analysis was conducted, particularly with respect to the factors identified as having large influence on activities and participation. This iterative process continued throughout data collection until no new information emerged. The transcribed interviews were imported into an NVivo 7™ (a qualitative data analysis program), read and re-read several times, and coded at several stages and levels. Four transcripts were also coded by separate individuals familiar with the process of open coding (Hutchinson) for investigator analytical triangulation, and coding examined for concurrence. Two hundred and eighty-six initial codes that described factors were generated as a result of this process. After several levels of coding, the codes were reduced to include 8 concepts: physical accessibility, individual attributes, adapting, supports, social context, experiences, weather, and physical ability. The “supports” concept was divided into 5 categories - devices, organizational, income, transportation, and relationships.
Table 1  
**Demographic characteristics of 24 participants**

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Educ</th>
<th>Marital Status</th>
<th>Emp</th>
<th>Inc</th>
<th>Comm</th>
<th>Resid</th>
<th>Caregiver interviewed</th>
</tr>
</thead>
<tbody>
<tr>
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<td>M</td>
<td>U</td>
<td>M</td>
<td>P</td>
<td>1</td>
<td>Res</td>
<td>M</td>
<td>Yes</td>
</tr>
<tr>
<td>54</td>
<td>F</td>
<td>P</td>
<td>M</td>
<td>F</td>
<td>3</td>
<td>Res</td>
<td>S</td>
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<td>60</td>
<td>F</td>
<td>U</td>
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<td>R</td>
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<td>R</td>
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<td>U</td>
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<td>R</td>
<td>2</td>
<td>Rur</td>
<td>S</td>
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<td>2</td>
<td>Res</td>
<td>R</td>
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<td>Res</td>
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<tr>
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<td>P</td>
<td>M</td>
<td>R</td>
<td>2</td>
<td>Res</td>
<td>S</td>
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<tr>
<td>30</td>
<td>M</td>
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<td>S</td>
<td>U</td>
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<tr>
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<td>2</td>
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<tr>
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<tr>
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<td>W</td>
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<tr>
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<td>R</td>
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<td>R</td>
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<tr>
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<td>-</td>
<td>Res</td>
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<tr>
<td>91</td>
<td>F</td>
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<td>M</td>
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<td>F</td>
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<td>U</td>
<td>1</td>
<td>Rur</td>
<td>S</td>
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</tr>
</tbody>
</table>

**Abbreviations and Interpretation:**

Gender: M=male; F=female  
Marital Status: S=single; M=married; W=widowed

Educ = Education: p=primary; S=secondary; U=undergraduate; P=post-graduate

Emp= Employment status: P=part-time; F=full-time; U=unemployed; R=retired

Inc= Income bracket: 1= lowest; 2=middle; 3=highest

Comm= Community: U=Urban; Res=Suburban residential; Rur=Rural

Resid= Type of residence: S=single family dwelling; M=multiunit dwelling; R=Residential home
For a better understanding of the qualitative analytical process, we present the following flowchart and example of coding and analytical steps undertaken under the concept of “supports”:

**Participants’ own words**

**Open Coding of Transcripts to produce Codes**
Examples – ‘machines,’ ‘technology,’ ‘public transportation,’ ‘private transportation’ ‘wheelchairs,’ ‘families,’ ‘friendships,’ ‘employers,’ ‘spouse,’ ‘pensions,’ ‘programs’

**Selective Coding to produce Categories**
Examples – ‘devices,’ ‘relationships,’ ‘transportation,’ ‘income,’ ‘systems’

**Higher level selective coding to produce Concepts**
Example – all the above categories are ‘supports’
We also ranked reported factors through various quantitative methods. For illustration purposes, Table 2 describes the top rankings as identified through each of the different methods of data triangulation described above. Terms used were provided by participants, and in brackets are the concepts they lie within. Column 2 lists “large” factors identified as such directly by participants in their interviews. The most frequently identified large factors are listed in rank order, showing the top five. Column 3 shows aggregate results of member checking, whereby participants listed their top 10 important factors. The potential impact of each identified factor on individual domains of the instruments (P-scale and Barthel Index) was ascertained by tallying and averaging converted data, and adding up effects all domains of each instrument. Factors having the largest impact overall on each instrument, negative or positive, are listed in Columns 4 and 5.

Considering the overall rankings obtained from the entire group through these methods of triangulation, the factors identified as having the greatest impact on activities and participation lay within the concepts of physical ability, individual attributes, physical accessibility, and supports, particularly devices and transportation.
Table 2  
*Top ranking factors by various methods*

<table>
<thead>
<tr>
<th>Large factors</th>
<th>Top 10 factors</th>
<th>Factors with greatest effect on P-scale</th>
<th>Factors with greatest effect on BI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  Impairment</td>
<td>Personality</td>
<td>Personality</td>
<td>Adaptive equipment</td>
</tr>
<tr>
<td>(physical ability)</td>
<td>(individual attributes)</td>
<td>(individual attributes)</td>
<td>(supports – devices)</td>
</tr>
<tr>
<td>2  Accessibility</td>
<td>Transportation</td>
<td>Accessibility</td>
<td>Home modifications</td>
</tr>
<tr>
<td>(physical accessibility)</td>
<td>(supports-transportation)</td>
<td>(physical accessibility)</td>
<td>(physical accessibility)</td>
</tr>
<tr>
<td>3  Personality</td>
<td>Equipment at home</td>
<td>Impairment</td>
<td>Impairment</td>
</tr>
<tr>
<td>(individual attributes)</td>
<td>(supports-devices)</td>
<td>(physical ability)</td>
<td>(physical ability)</td>
</tr>
<tr>
<td>4  Wheelchair</td>
<td>Accessibility</td>
<td>Wheeled mobility aids</td>
<td></td>
</tr>
<tr>
<td>(supports – devices)</td>
<td>(accessibility);</td>
<td>(supports – devices)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(physical ability)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5  Equipment at home</td>
<td>Transportation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(supports-devices)</td>
<td>(supports-transportation)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In brackets are the concepts into which each factor falls.
**Discussion**

Relative importance of factors affecting activities and participation for the study population were determined through this study. Through various methods of triangulation, factors having greatest impact were identified. From this list, one would then have to determine which would be important for inclusion on scales measuring activities and participation. Different factors were reported to impact upon the Barthel Index which measures activities of daily living (primarily home accessibility and equipment in the home), as compared with factors impacting upon the P-scale, which measures participation in the community (which include transportation, and individual attributes). Physical ability is a factor that had impact on both, and determined eligibility for inclusion in the study. Interestingly, many participants did not report this as a factor affecting daily activities, having already integrated their abilities into their identities.

Bryman (2006) described rationales for using mixed methods to include instrument development, context, and utility. We have described a study in which mixed methods are used to answer a question important for instrument development that could not have been answered with a similar degree of certainty if either a qualitative or quantitative approach were used exclusively. The study presented above could have been conducted entirely in a post-positivist paradigm, but in the absence of the personal perspectives of each participant, understanding of influential factors on activities and participation would
have been more patchy and incomplete, and the authenticity of results questionable. We would argue that the question could not have been adequately addressed without mixed methods; therefore we term the study an essential mixed methods study.

Grounded theory aims to develop an inclusive general theory from the ground up, thus translating practice into theory (Hutchinson 1993). Tools themselves arise from theoretical frameworks. The Barthel Index and Participation Scale fit into the framework of the ICF. Hence, when using these tools, one could be said to be conducting verificational research (Hutchinson 1993) which is deductive, and moves from general theory to a specific situation (theory to practice). As indicated above, the ICF framework holds that “functioning and disability is conceived as a dynamic interaction between health conditions…and contextual factors…and both personal and environmental factors” (WHO 2001). Our participants verified that such factors impact upon functioning and disability, and helped us to understand contexts, allowing us opportunity to improve on reporting of existing instruments, through identifying the factors most likely to influence scores. In a way, this study has the ability to test theories against each other.

**Concluding remarks**

It seems artificial to confine the human intellect and understanding to only one paradigm when conducting research. Human understanding depends on the ability to relate with divergent points of view. It is through this ability that humans demonstrate empathy. Thus it does not seem reasonable to require researchers to adhere to one paradigm if the
research question calls for multiple points of view. Even when a fully positivistic clinical study is completed, with double-blind, placebo-controlled randomized controlled trials, clinicians recognize that the findings may not necessarily apply to any given individual, as responses to interventions are individual. Therefore, we would encourage that researchers consider the many possible perspectives from which to address a question, and to incorporate the relevant methodologies into study design.

Acknowledgements

The authors would like to acknowledge the Southeastern Ontario Academic Medical Association and Clinical Teachers Association at Queen’s University for funding this research. Also, thanks to Queen’s University Inter-professional Patient-Centred Education Direction for a student stipend.
References


Chapter 3

Exploring how factors impact the activities and participation of Persons with Disability – Constructing A Model through Grounded Theory

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Margo Paterson, PhD, Associate Professor, School of Rehabilitation Therapy, Queen’s University

Challenge

Since the 1970s, with the rise of the independent living movement, initially in California, Texas, and Massachusetts (Boschen 1998), new approaches, including self-help and peer support, led to new processes of service delivery. Health professionals recognized the importance of working together in collaboration with persons with disabilities towards their goals. This interaction is now termed “inter-professionalism.” By far, most studies have focused on the Spinal Cord Injury (SCI) population. 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 personal influences on independent living (Boschen 1998). Other scholars have suggested that it would be interesting to analyse the relationship between
environmental factors and activities and participation to understand more about factors impacting upon function (Voorman and 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, cultural values’ (Nosek and 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 such as in Christiansen and Baum 1997. In recent years, two prominent models have emerged to describe the interactions between personal and environmental factors, and the effects of these factors on activities of people, within the home or in the community. The International Classification of Functioning, Disability and Health (ICF, WHO 2001) and the Disability Creation Process (Fougeyrollas et al. 2002) both stress the importance of interaction between personal and environmental factors on activities. This interaction has become so recognized that even the American Psychological Association website, which provides guidelines recommended by The Qualitative Report, states: ‘the environment is
frequently overlooked as a major source of limitation, even when it is far more limiting than the disability’ (APA 2007).

One admitted problem in the literature is that the assessment of activities and participation has generally been value laden (DeJong and Hughes 1982). What is required is a better understanding of what matters to persons with disability, who may be impacted by many factors. Whiteneck (1996, p. 180) indicated that ‘success is in the eye of the beholder’, and that ‘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 participants feel are important to them. Understanding those factors which 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.

**Research Question**

How, and what entities or factors are perceived by persons with mobility limitations to affect their activities and participation?
Methods

Grounded Theory methods were used to explore experiential knowledge of persons with disabilities, after a period of rehabilitation and adjustment of at least one year of community living. These methods allow researchers to gather data, and then systematically develop the theory derived from the data (Dey 1999). Concrete experience and reflective observation were explored through interviews of participants. Data collection activities associated with the tradition of Grounded Theory were used (Creswell 1998), with the viewpoint that reality is constructed by individuals, and that multiple realities exist.

Ethical 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 if eligible for participation. Anonymity of participants was assured in all publications and confidentiality was maintained at every step after consent forms were signed.

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, from the catchment area of Kingston and surrounding areas in South Eastern Ontario. A range of participants were chosen, 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, rural and urban residence. 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 by the primary author (Folstein 1975).

Participants were interviewed in person at mutually agreeable times and places. Immediately prior to interviews, demographic information was obtained. All interviews were conducted by the primary author. The semi-structured interviews incorporated two measures into the interview guide: the Barthel Index (Mahoney and Barthel 1965), a measure of activities of daily living; and the Participation Scale (van Brakel et al. 2006),
a measure of community participation. 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. Where feasible, triangulation through caregiver interviews was pursued. Interviews of caregivers took exactly the same format as those of participants, substituting the participant’s name instead of ‘you’ for open questions.

All interviews began with the 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. After this question was thoroughly explored, they then answered questions in the same vein for each domain of the above measures, to ensure that factors were explored thoroughly. Activities 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 1 to 2.5 hours, with the majority lasting at least 1.5 hours, at locations chosen by participants.
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. These were entered into the data management program NVivo 7™ after each interview. Data were then 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 (proceeding from facts to conclusion), and reductive (bringing back, or comparing back) process that organizes data for the construction of themes, descriptions, and theories (Walker and Myrick 2006). Though Glaser and Strauss introduced the concept of Grounded Theory, their thoughts on methods eventually diverged. Coding was conducted according to Glaser (as opposed to that of Straus and Corbin 1990), in 2 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). This was done within NVivo 7™. Selective coding involves organizing the coding process around core categories, or substantive codes. Memo-ing was also employed throughout, as part of data analysis. Glaser’s methods emphasize ‘what the subjects themselves are saying’ (Glaser 1992, p.50).

Open coding was also performed independently by 3 other individuals on 4 transcripts, in an effort to include analytical triangulation. Coding between the primary author and these
other individuals was comparable. Higher order concepts were reviewed and discussed with two other investigators. Categories, concepts, and models were presented to a reference group of graduate students and faculty for feedback.

**Results and Discussion**

**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 y, median and mode 60 y). This reflects the demographics of the community from which participants were drawn, being in the top 5 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 9 males, and 15 females, perhaps reflecting the fact that females live longer in Canada (life expectancy of 82.6 years as compared to 72.8 for males - Statistics Canada 2006), and that older persons have more disabilities. Eight were married, 8 single, and 8 widowed. All were living in the community, either in single family dwellings (15), multiunit dwellings (6), or residential settings (3), in which meals and housekeeping were generally provided. Participants in all settings reported availability of additional caregiver assistance. Caregivers of three participants were interviewed, with responses reflecting those of the participants themselves, with one additional factor identified in the case of two participants.
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: 11 were in the lowest income bracket, 9 in the middle income bracket, and 1 was in the high income bracket. With respect to employment, two were employed full-time, 2 employed part-time, 4 were unemployed, 1 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 et al. 2006).

Sample

Figure 1 illustrates the number of large factors identified by successive participants, and the point of saturation at which recruitment ceased. The graph clearly shows that most, eighty percent, 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 24th participant, although new smaller factors continued to be identified by participants, due to significant individual variation and uniqueness.

Participants were eager to share their experiential knowledge. Their words are italicized 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
Figure 1. Number of NEW important factors identified by successive participants, until saturation.
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 domain with the question “are you comfortable meeting new people?” in the Participation Scale. 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. One participant indicated some hesitancy when meeting new people: “I mean sometimes I’m a little shy at the beginning, but for the most part, I don’t mind meeting new people (P10).” A mix of residential settings existed in our study population - three participants lived in urban neighbourhoods, 14 in residential suburban areas, and 7 in rural settings.
Summary of analytical process

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

Participants’ own words

Open Coding of Transcripts to produce Codes

Selective Coding to produce Categories

Combining categories in Higher level coding to produce Concepts

Theoretical Coding to look at interactions between concepts from participant quotes

Theoretical coding led to generation of a Model

Open coding

Open coding led to 322 codes altogether, though 36 were related to domains on the outcome measures used to guide the interviews. Therefore, 286 codes were generated by participants that related to factors affecting activities and participation. 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. Finally, categories were analyzed and fit into 8 higher order concepts or themes, which were: 1. Social Context  
   2. Physical Accessibility  
   3. Weather  
   4. Physical ability  
   5. Experiences  
   6. Individual attributes  
   7. Supports  
   8. Adapting  

1. Social context covers the categories of atmosphere, self-consciousness, attitudes, general population, schedules, apathy, balance, being single, counsel, country, crowds, encouragement, epidemic, expectations, fairness, fitting in, gender, high risk, interaction, normalcy, expectations, obligations, assistance, population density, predictability, prejudice, quality of life, relaxation, residence, smoking, social context, social pressure, standing, stigma, teamwork, time, uncertainty, unmentioned, and workplaces.

2. Physical Accessibility covered the categories of barrier, space, parking, home setup, outdoor access, and access of heritage buildings, housing, hotels, restaurants, terrain, workplaces, and ramps.

3. Weather includes the categories of winter (ice, snow), cold, rain, heat, humidity, that cover climactic conditions.
4. **Physical Ability** combines impairments and management. **Impairments** includes categories concerning limitation, safety concern, abilities, 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, and weight, while **management** includes beneficial medications, beneficial procedure, breathing equipment, course, distraction, emergency, hydration, medical suppliers, protection of body, rehabilitation team, remedy, side effects, surgery, treatments, ventilator, diet, and nutrition.

5. **Experiences** includes aging, disability experiences, 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, previous experiences, regret, role model, stress, teasing, thankfulness, unease, unexpected benefits, unfamiliarity, widowhood, and worth.

6. **Individual attributes** includes the categories of choices, dreams and desires, interests, personality, 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, role, sacrifice, self-expression, self-sufficiency, social consciousness, spirituality, spontaneity, susceptibility, teaching, unacceptable, vigilance, worth, certification, educational resources, knowledge, staying current, and independence.

7. **Supports** subdivides into five types: **Organizational systems** (services, arrangements, delivery, efficiency, legislation, mail, regulations, rentals); **Transportation** (car, bus, distance, rest spots, train); **Relationships** (family, spouse, helpful contacts, communication, closeness in relationship, keeping in touch, friendships, neighbours, support, understanding, church, club, peer group); **Devices** (Adaptive equipment, computers, assistive technology, appliances, brace, custom made, devising and designing, incontinence pads, machinery, portability, repair, specifications, splints, supplies, telecommunications); and **Income** (benefits, insurance, pensions, caution, cost, expenses, funding opportunity, hiring).

8. **Adapting** includes categories relating to technique, acceptance, arrangements, thankfulness, coping, asking for help, arrangements, back-up plan, convenience, planning, emergency preparedness, ergonomics, exercise, flexibility, future improvising, devising and designing, modifications, pacing, prevention, problem solving, prudence, safety concerns, strategy, and clothing choices.
The substantive coding steps were conducted without adherence to any particular model other than the framework of body structures and function, activities, and participation, provided by the International Classification of Health, Disability, and Functioning (WHO 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. What follows are relationships that were noted. We first describe the general setting in which our participants live and the environment they face collectively. We then describe the range of physical impairments in our population, delve into other personal factors, then provide descriptions of supports and adaptation helpful to our participants’ activities and community participation. For ease of discussion, we review the literature according to 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, relating the literature to our findings. A theoretical model is then presented that summarizes these relationships and concepts.
Social Context colours experiences

It is important to understand the social context in which our participants live. In this section, we present examples of positive and negative aspects of the social environment in which our participants live. Social barriers and attitudes have been identified to affect community reintegration (Dijkers 1998; Boschen et al. 2003). Positive attitudes can facilitate social participation according to Noreau et al. (2002), who maintained that social environment has a crucial influence on quality of life (QOL), which ‘is something relative which the individual measures in relation to his or her needs and expectations’ (Stensman 1994, p.417). Having a disability alone does not necessarily affect QOL, nor does level of 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 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’ (p. 835), and social support, may affect QOL (Dijkers 1997; Wee and Schwarz 2004).

Within our study population, the vast majority of participants said that they did not allow negative attitudes to influence their outlook much; however, difficulties with respect to completing basic education, finding employment, and socializing were reported. This is similar to findings by Stensman (1994). On the whole, our participants reported favorable attitudes of others, though the need to educate able-bodied persons about certain aspects of disability was evident. Everyone with a disability functions within the social milieu
around him, be it positive, or negative. Participants faced similar “social pressure” as would persons without disabilities, in their activity choices; the pressure to socialize with friends and family “sometimes takes over (P6).”

This study occurred in a mid-sized city, with a large rural catchment area. Setting may influence the types of activities one does. For example, in the country,

“You don’t think about where the water comes from or where it goes or anything, until of course, the well runs dry, or something happens with the septic tank and it’s not flowing, but...the toilets back up in the city...(P19)”; and

“You eat out more in the city...go to movies and things like that. Whereas out here, you do more reading...more walking...In the city,...you’re on top of everything.... Living in the country you have to drive...it’s a totally different life really....I think you spend more time...gardening and cutting grass...and maybe with your neighbours (P22).”

Some participants living in rural areas described differences in social atmosphere as compared with living in the city:

“People in the country tend to have a more balanced sense of time...they’re not always rushing from here to there; you can drop in on them. They’ll stop what they’re doing and talk...the moment something goes wrong out here, there are dozens of people rushing in (P19).”
The size of the centre in which the study was conducted was itself thought to influence social atmosphere, according to one participant, who used to live in a city where

“you minded your own business. You went to work, you came home, you had your small circle of friends, but that was it. You know, you didn’t say ‘hello’ on the street….That changed dramatically when I moved here. All of a sudden, people were saying ‘good morning’ and I’m thinking, ‘do I know this person?’ and I got so used to the idea of saying ‘hello’ to people (P4).”

Some participants chose to live in residential home settings, and have their activities influenced by this particular type of setting, as many of these residential establishments hire people to organize outings for residents. “There’s an activity director, and it’s her job to do these things (P22).” Dijkers (1998, p.8) felt that the type of abode in which 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. Our data does not support this judgement, as some participants who chose to live in such places continued their desired activities and levels of participation in the community. One participant living in a retirement home increased her activities in the community once a power wheelchair was obtained, suggesting that other factors besides living abode may contribute to community participation. No participants from nursing home settings were recruited, and responses may be biased because of this. It may be possible that those in nursing home settings are not able to access caregivers, or to direct and organize their own care needs. Inclusion of
persons from nursing home settings might allow one to delve further into barriers to community living if the study were so designed.

The literature suggests that the home setting is more than just a physical abode. According to Reid et al. (2003 pp.187, 188), the home is ‘a psychosocial environment constructed through the activities conducted’, and that ‘domestic physical and social circumstances have a greater influence on occupational performance than the ability or inability to perform a number of activities independently.’ This alludes to one’s roles, or participation, suggesting an interaction between one’s roles, and one’s home setting, an association supported by our participants’ responses. This was seen clearly in the case of one participant, who assumed the role of president at a residential home, and reported role-consistent interactions with other, particularly new, residents.

Despite the advances made in human rights and social awareness in our society, some negative attitudes towards persons with disabilities persist. When first meeting people, many participants described 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(P5).” “Some people...just don’t know how to take you [laughter] so they ignore you...they’re taken aback sometimes, when you say hello (P9).” Participants spoke about “people’s pre-conceived notions,...the way certain people would introduce themselves,...the sound of their voice, you know, talking like they’re talking to someone who’s slower, like little kids (P10),” and how they handled this. “I’m obviously not gonna want to talk to the person for much
Often, participants reported being ignored, when with other people: “People tend to be put off by anything that’s out of the ordinary…. When me and my wife go shopping, as a rule, they normally approach her to ask difficult questions (P23)” ; “somebody that doesn’t know you…they don’t talk to you; they talk to the person behind you…once you’re in a wheelchair, you’ve lost your marbles completely (P21)” ; “as soon as they find out you’re actually disabled, they won’t talk to you, they’ll talk to the…person that’s with you….One in…20 people are like that (P24).” One participant encountered different attitudes depending on first encounter circumstances:

“I don’t like going into a room that’s already full of people…I want to be there early, then I could sort of get in and be there first…You know 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....I put that stuff as to somebody [who] just has an attitude problem (P13).”

Some noticed negative attitudes towards the elderly – “some people don’t have any patience with older people (P11).” Another participant felt that our society seems to support certain members of society more than others – “we are now providing for nursery schools...and forget about the other end of the spectrum completely (P21).”
One participant who had previously repaired airplanes, recounted a particularly telling encounter:

“There was a young doctor, one of these doing their internship...and he’s looking at the X-ray that they’ve just done on my spine, and he said ‘I can see some old damage on here...how did you do it?’ I said ‘I fell off an airplane.’ Well, he looked at the nurse and she looked at him, and their eyes rolled, and then in that voice which they keep for lunatics [laughter] and small children, he pats me on the shoulder and says ‘well dear, why don’t you tell us, what were you doing on the tail of an airplane?’...He looks and he sees an old woman, and she can’t even walk properly, and so obviously her mind’s gone too (P19).”

Sometimes, participants expect to encounter negative attitudes, and may avoid certain situations such as weddings. For example, one participant described weddings as

“a happy occasion; it’s not for grown women in a wheelchair...I like to be at weddings, but it’s just that when I can’t go in and walk and you know, take my part properly, in a nice dress and walk up too with the fancy shoes and all... I just don’t put myself in that limelight to be shunned (P8).”

In crowds, “you don’t exist if you’re in a wheelchair (P24).” If not ignored, the topics of conversation might differ from the usual:

“It was more... ‘how fast does your chair go?’ or ‘how often do you change tires?’ You know, car type questions...I’m not sitting here asking you about your
car, ‘how often do you change your tires or your oil?’ ...They don’t know what to talk about and don’t know what to SAY... look beyond the chair (P12).”

According to some participants,

“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....I’ll never put myself into a position so that the sight line is such that I’m going to put a kink in my neck (P5).”

Participants reported facing bigotry and stigma:

“We ARE stigmatized...I got on a bus...you see the people inside, and one guy’s eyes rolled...I got on, and he got off before me, and as he was leaving the bus, he was looking at me. Outside the bus, he’s still staring at me (P12).”

In looking for work, such stigma seemed obvious. A few participants reported problems of prejudice, and of “potential employers not being familiar enough with the abilities of people with disabilities (P6).” Participants found it difficult to hide their disability, nor did they feel they should. “I can’t write my CV without you figuring out that I’m in a wheelchair...I mean I take my CV here and there, ... but still, no interviews (P12).” This participant wished that people would “look beyond all that...look inside. You know, the skill set is the same (P12).” Another shared that

“you tend to get pre-judged before you ever get the opportunity....If I was in the retail business, I wouldn’t hire somebody with a cane, or that had a disability,
because I know from experience that people are put off by that. And if I’m trying to sell to the general public, is that a good business decision on my part (P23)?”

If one requires attendant care, “it’s hard to find employment…the employer would have to be willing to supply attendant services as well (P10); “nobody’s going to hire somebody and pay two people (caregiver of P10).”

Participants realized their own limitations when it came to work duties - “I don’t think I’d have a chance of getting a job…I couldn’t go to the areas that...would be needed (P21).” Those who had not yet searched for jobs were optimistic about opportunity: “I think if you really wanna work, you can find something... I think they don’t want to risk discrimination (P24).” When it comes to finding employment, many factors come into consideration. Researchers have tried to ascertain predictors of ‘productivity’, and have found predictors such as physical therapy, age at onset, Barthel score, education, and housing adaptations (Dunn 1990). Some of these may indirectly reflect employers’ attitudes.

Despite the attitudes of some towards persons with disability, participants generally reported encountering positive attitudes: “I don’t think anybody who’s handicapped could get around without the people who are so good, so thoughtful.... There are...occasional people who are just rude and thoughtless, but they’re the kind who are rude and thoughtless to everybody (P19); “whether they’re young children...or
teenagers...all ages, they’re always willing to help (P14).” Others indicated “there are MANY people out there who are very good...I’m having a hard time...to ASK for help (P15).”

However, it is sometimes difficult to see where helping ends and intrusion begins, as is described by the following range of responses to assistance: “People are...quite kind...I can open the door myself and I can hold it...but if they want to open the door...I thank them (P22)”; “generally people are very helpful...some of them will turn around...and push your wheelchair...they don’t tell you and all of a sudden, you think you’re out of control (P17)”; “one of the things that I find frustrating is that people try to help you...when you don’t even ask...they open the door, then stand in the door. You can’t get by them [laughing] (P23)”; to “a lot of people will go out of their way, who go WAY beyond what they need to do, which is a KIND of lack of respect, or a discomfort, maybe (P2).”

In reality, social context appears to be a product of interactions between people, as described in the following example:

“I’m thinking ‘Am I being stalked?’... and they would come over and say ‘Can I get you something?’...you DO meet some very nice people.... But there are times where I’ve gone into a new place...and you can tell they’re not quite sure how to handle you. And until I speak and make myself clear, they sort of stay back....I’m sure that if I went around looking like gloom and doom, they would literally go in
the other direction. So yeah, I think it has SOMETHING to do with YOUR attitude (P4).”

Sometimes, when it comes to respect shown by others, “the fact that I have a regular job and work...makes a big difference (P23)”, as does “self confidence...not being afraid to express ideas (P6).” Some participants maintained that personality influences the way others view them. “He gets a lot of respect from...his ability to cope with his disease, how he handles everything related to that (caregiver of P13).”

Gender and marital status affect activities

“I think men are worse than women...they don’t want to ...appear infirm...observing some of the men here, that should be using a cane or walker, and aren’t....I haven’t found one yet over 70 (P22),” laughed one elderly female participant who lived in a residential home, reflecting the demographics of women outliving men, and perceived differences in behaviour. Reid et al. (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, schools, classrooms, libraries, community centres, swimming pools, and local parks, which prevented them from full participation in their children’s activities.
Being single was a factor in whether certain activities were performed or not. For example, being single meant that meals were often taken alone. Some participants were comfortable with doing so, while others “hate eating alone (P21).” Being single might mean it is easier “to go places” for some who “don’t have a husband or children (P12).” People who were widowed reported a change in the types of activities because of the change in social status - “I’ve 2 couples that I used to [socialize with],….they have their own things that they do, and of course I’m a single, I don’t (P8).” Another explained:

“It’s quite strange that there are an awful lot of people who are friendly with you when you are a couple. You know, they like to have…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…I found the importance of women friends…at one point it [being widowed] was a very, very large factor, but it’s gradually decreased over the years (P19).”

Predictors of living arrangements, an aspect of social context, have been found to include age, communication problems, marital status, household income, hours of paid personal care attendants (Dunn 1990). Both gender and marital status are important factors in distribution of resources, and how life is experienced (Dyck 1995).
Inaccessibility is a common barrier and assisted by legislation

Much has been written about physical accessibility, also commonly referred to as accessibility. Architectural barriers have been found to affect community reintegration (Dijkers 1998). Participants recognized that compared with other countries in the world, “Canada has got to be one of the most accessible (P4)”; “we’re very lucky here in North America (P14).” Improvements have occurred; in the past, “we were more hidden...if you couldn’t get into a building, well I guess you just didn’t go (P15).” “Most places now, have just become, in the last 15 years or so, geared to people in wheelchairs (P13).” “It sure is a heck better than it was 30 years ago, but every so often, when you let your guard down, you’ll run into a snag (P6).” The Government of Canada has recently developed accessibility standards (Treasury Board of Canada 2006).

Steinberg et al. (2002) identified accessibility issues that faculty members with physical disabilities contend with, such as entering campus buildings through loading docks, finding themselves trapped in locked buildings after hours, 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 are often not clearly marked. Lifts on shuttle buses may be unreliable, and faculty must schedule extra travel time. Destinations may be inaccessible, or accessible vans may not show up. Frequently, there are no acoustic devices or Braille signage to enhance accessibility for deaf or blind persons.
Faculty members in our participant pool also reported similar challenges. Unfortunately, when it comes to removing physical access barriers, “there are still plenty of people who have an attitude problem, like ‘why do we have to BOTHER with this (P2)?’” A specific instance was described by one participant:

“one of the things I used to do is ... oversee the drawings and slope of wheelchair ramps... one time this fellow said ‘well I think we should send all these handicapped people to Saskatchewan where it’s all flat. We don’t have to worry about ramps.’ And then I thought, ‘what an attitude (P14).’”

Some mentioned current legislation regarding accessibility – “there’s a law that a NEW place has to have it (P17).” Another 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).” Travel was reported to be easier in North America than elsewhere, “especially in the States – they have what you call rest stops (P3); “most European countries are not accessible (P4).” However, “one person’s definition of accessibility isn’t the same as another’s (P6); many so-called accessible places may be accessible to some, but not others. For example, a participant reported difficulties with some automatic doors designed for easier access. “You have to... back yourself in... then press it and back up and jet in because ... half the way in, the door will close on you (P24).” Often, participants who usually use power wheelchairs or scooters must also have manual wheelchairs available for use, because of problems with access for
power mobility devices - “if I took my portable wheelchair, somebody could lug me down the steps...I can’t get in there with the power chair (P16).” According to one participant, who assessed power wheelchair access in the local community, “only...25% of the stores were accessible (P24).”

Difficulty negotiating terrains such as those found in gardens and other outdoor areas were reported by many. “How steep a hill” is, or how rough the terrain is can make a difference... “my hands will fall off...if whatever surface I’m driving over is really bumpy (P10).” Rural roads often do not have sidewalks:

“If I’m walking down to the village, I have to walk on the road itself, which is why somebody dropped me off one of those hydro jackets...the orange thing....It’s a large factor, to have sidewalks that are smooth. It’s important to have curbs at junctions that slope down (P19).”

Grades, road humps, and other barriers were reported by participants and their spouses. Some temporary barriers are caused by construction – “you won’t discover ‘til you’re halfway down that block that you can’t continue and you have to go back (P5).”

Sometimes, the design of roadways and ramps is a problem.

“I think everybody should be put in a wheelchair for a day...and I think that a lot of this would be eliminated....They’re making ramps that are not ...the right way....Interlocking bricks are the worst thing that ever happened...it’s just like a plowed field, going over it in a wheelchair (P21).”
said one participant. Outdoor accessibility is also affected by weather conditions, described in the next section.

One variant of outdoor accessibility includes parking access. Participants reported “a real shortage of spaces because there are too many permits in circulation (P6).” One participant’s “greatest complaint against people is using the reserved... parking spots when they really don’t need to (P9).” Sometimes, parking spots are too far away.

Some buildings were usually expected to be accessible. “If we’re on the highway, most truck stops...are accessible (P10).” Government buildings and “churches usually have ramps (P20).” Nevertheless, some participants may experience difficulties, as reported by one participant in regards to access to a hospital and a government building- “half the time, if my son didn’t push me, I couldn’t get over this lip about [1 inch] high” and “it’s a government building, and I think it should have easy access...they have a push to open the door, but it’s like a civil servant, it doesn’t work (P17).” One participant was prevented from attending classes at a university for a couple of weeks, because of access barriers. Accessibility determined where participants frequented, and their participation in certain activities: “I typically don’t go downtown, ‘cause you can’t go anywhere...It’s seldom that you can’t be accommodated by someplace else that is accessible (P23); “I went to one wedding when I was in my wheelchair...their church was wheelchair accessible... Now that was a huge factor in whether I attended or not (P4); and
“there’s only certain restaurants we can go to...the tables are so low that my
wheelchair can’t fit under...or the aisles are so small that they have to sit me
somewhere where a table normally isn’t, so it brings more attention to you
(P24).”

Participants preferred to frequent establishments that are “worthy of it (P20).” Some
reported difficulties finding out ahead of time whether or not certain establishments were
accessible, and felt singled out:

“I’d like to see them put whether or not it’s accessible...a lot of them, they are
like southern Negro, you get in the back door...if they’re going to sell tickets, 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).”

The need to plan ahead with respect to accessibility was clear, especially when venturing
into unknown territory: “If he wanted to go somewhere, [his workers] would ... scout out
accessibility of the bathrooms (caregiver of P10)”; and

“I always ask people when they ask me to go somewhere with them ‘where is the
washroom?’ ...because I don’t do stairs. I’ll occasionally crawl up on my hands
and knees...I’m not prepared to go on my hands and knees in public (P19).”

Other considerations besides physical access of buildings are also important. “Sometimes
you won’t go if it’s very busy...like Saturday afternoons. You find harder times around...
the Christmas season, ‘cause they tend to pack everything in the aisles [chuckling] (P23).” One participant reported significant difficulties with accessibility, encountered during travel in Europe:

“The train was not accessible…hotel room wasn’t really accessible…the dining room had a ramp but they actually had to push me up, it was so steep…I was on a concrete block in the middle of all this track…I had to hop over the tracks (P12).”

For another, “the biggest problem for me in hotels is the long carpeted corridors [laughing] because if I’m tired…it’s really hard…I want those nice marble floors [laughter] (P2).” Even with preparation, difficulties might arise, such as at one hotel:

“I fell…they assured me that they’d have it….but they don’t know how to put it on…I went right on…the marble floor….They say it’s a room for the disabled. Well …the bars aren’t even in the right place (P21).”

One participant advised “if they don’t have accessible rooms… you shouldn’t have to pay for a bigger room because you need it, so you…have to bargain with them (P24).”

By far, the most important access was to participants’ own homes.

“I am currently looking for an apartment that is adapted to a wheelchair, because I find they have widened a couple of doors here, but I cannot get into the bathroom with the wheelchair…The counters in the kitchen are much too high….If I’m sitting in a chair, it’s almost impossible, ‘cause you can’t get down into the sink (P4).”
This phenomenon is referred to as ‘environmental centralization’ (Reid et al. 2003, p.192). Participants often needed to make modifications, describing beneficial outcomes:

“I have patio doors over there to go out onto the deck and they have a flat sill...things like that have really, really meant a lot... before, I needed help to get out, whereas there, I can get out myself, lock the house, and get in myself (P9).”

Accessibility was also felt to be a safety matter. “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 accessible housing environments spent approximately double the amount of time outside their home than those with housing barriers; once these barriers were removed, they spent more time in the community, though they found that home accessibility only explained 10% of the variance in work and education. The literature indicates that 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. 2003). In fact, one of our participants expressed enormous appreciation for the accessible apartment that he had lived in for over twenty-five years.

Invariably, participants reported difficulties with access to others’ homes. This influenced where socializing occurred. “I can’t get into anybody’s home. So they come to me, or...we all meet downtown...in a location where they know I have the freedom to move around just as much as they do (P4).” In fact, one participant, who was relatively mobile, and knew others who were less mobile, stated
“I always have to go to their house; they have accessible houses...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).”

Many indicated that poor accessibility often deterred them from visiting friends, either because walkers have to be left outside, or wheelchairs cannot get in - “if they’ve got steps I can’t visit them. ...I had to give up bridge...I’m getting back into another group but it’s because we’re going to meet...in a place that’s accessible (P21)”; “one limiting factor is the type of houses that people live in....If they’ve got a proper railing and everything, I can get in, but it’s a hassle. And then often their bathroom isn’t on the same floor (P23)”;

“I know the railway is very accommodating, and I know they can accommodate the chair, but it’s at the other end...all my families’ houses would be inaccessible,...MOST of them have stairs (P9).”

Participants reported their efforts in trying to improve accessibility for others. “This building is accessible now...I had to work very hard to make it accessible (P2).” Reid et al. (2003) also reported that many persons with disability many entertained in their homes because of access issues, and were responsible for neighbourhood changes with respect to accessibility. Clearly, ongoing efforts to build a barrier free society with a focus on
Universal Design, intended to be usable to the greatest extent by all people without adaptation, would be beneficial (Christophersen 2002).

**Weather affects accessibility and physical ability**

Weather was a factor that was raised time and time again by the majority of participants. We include temperature in this category. Clearly, rainy, cold, or snowy weather affects accessibility, and many “don’t get out very much at all (P10).” “It isn’t that easy with a wheelchair in wintertime on ice and snow, so that’s a big factor (caregiver of P9).”

“Freezing rain” (P22) was reported to be particularly difficult and dangerous to negotiate in. One participant explained -“can’t go outside in the rain because of the power chair. ...It can...shut down. Instead of having the umbrella over top of me, I put it over top of here [joystick] (P24).”

Generally available mobility devices do not seem to have overcome this aspect of life in Canada. Available transportation options become particularly important when weather is a barrier. What follows are several quotations from participants regarding weather and how it influences activities:

“Winter is harder...walking outside with crutches is not good in winter...I have a motorized scooter that is pretty well all weather, but it’s not exactly pleasant [laughing] to be out in that. The manual wheelchair, it obviously doesn’t go anywhere (P2)”;

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“Once the nice weather is here, I’m out…. I’m out all summer long. When it starts to get very cold, or if there’s snow on the ground, these [power chairs] are not meant to be out. They aren’t heavy duty snow plows…my first chair…I got stuck halfway up the street, and a gentleman had to get out of his car,…and he walked me all the way back to the apartment, and I swore I’d never try that again. That was very scary…So from November ‘til…mid-April, … I’m not going out there looking for trouble….I prepare (laughing) – I stockpile books,…crafts…wool, and everything, so I’m ready for all my projects (P4)”;

“I don’t like the winter ‘cause it’s too hard to get around…if I want to go anywhere I get in the truck and go, but one has to remember when you get to the other end, it’s crappy…the parking lot is full of snow and sand (P6)”;

“I get my mail in the summer…I can’t in the wintertime, because I can’t get across the street with the wheelchair….I might stay in here two or three weeks, never go out the door, and then I’ll think ‘oh God, I’ve got to get out of here’ So I’ll phone…[the Access bus] and say ‘come and get me. I don’t care where you take me’ (P16)”; and

“Your tires cake up with snow, the rims get ice on them, it’s very hard to push; it’s hard on your hands…it’s like…instead of using your car in winter, you decide
to use your bike, so you’re hit by snow, winds, and sometimes you can hardly feel yourself move, or you CAN’T move because you’re so cold, so imagine it’s time to ride your bike all winter long...that’s a little of what it’s like...very hard on the hands. You can cut your hands (P12).”

Weather also affects physical health and abilities. Cold weather may have negative effects: “I get asthma in winter...Several times over the winter, I cancelled evening plans (P2)”; “I don’t think the muscles respond the same way (P9)”; “quite aside from fearing stability in the snow and ice, I just don’t think I’m able to walk as far (P5)”; “I can’t sleep when I’m cold (P24).” Some cannot tolerate heat – “if a place doesn’t have air conditioning in the summer, I can’t do it...I’d end up in the hospital (P3).” Rain, heat, and humidity also have individualized effects on some: “The dampness affects my bones, and it is a little depressing on a cloudy day (P8)”; and

“If it’s really...humid...even with the ventilator... it’s harder to breathe...If it gets hot, my hands...get kinda sweaty, so that makes it harder to use the mouse...If it’s cold or damp, I have problems with my hands...the cold makes my hands seize up, and then I can’t drive my chair...my hands get so cold that I get my attendant to drive my chair for me (P10).”

Weather seems to affect the behaviour of other people as well - “when it rains, you don’t want to go to the mall because all the handicap parking spots are taken (P23).” In general, winter weather seems to pose greater problems than hot, summer weather – “it’s
better when I’m hot because when I’m out I can get cooled down a lot quicker because I can drink a cool drink or put ice on my forehead (P24).” One participant summarized – “the weather, it’s probably a bigger factor in the winter than it is in the summer (P10).” Overall impact of weather on life is relatively small, even though it has a large impact in specific instances – “it might be 3 or 4 days a year, maybe 6 (P23); “the odd snow day would keep me in if I don’t really have to go out anywhere (P12).”

Physical limitations require more effort, time, and flexibility for activities

We describe the effects of physical impairments, to enable understanding of the range and impact of impairments affecting our participants. As already mentioned, persons with a range of conditions and severity of impairments were included in the study population. Some common impairments faced were reported. They included fatigue, pain, weakness, and impaired mobility.

Fatigue and limited activity tolerance was commonly reported by persons in all diagnostic categories, and through experience, they learn their limits. “Everything takes twice as long (P12)” ; “I don’t bathe as often…because it’s a major effort. If I have a bath in the morning, I’m kinda shot ‘til noon (P3).” The greater the physical impairment, the greater the effort required. Energy conservation is a strategy used to cope with such limitations:
“I don’t have sustained energy. I have short bursts of energy, where all of a sudden I feel I can do this, this, and this, and then all of a sudden, it all just comes to a dead halt.... 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),” and

“My body is played right out. It just seems to have no resiliency.... I just get SO tired that I couldn’t function...I know when I get tired I can’t think....I can’t enjoy my family or anything without energy (P8).”

Persons with multiple sclerosis in particular, reported unpredictable fluctuations in levels of fatigue, sometimes affected by weather, or “time of day. I could say ‘I’ll help you this Thursday’ and when the time comes...(P3).” Some find medications helpful. “I just can’t tell when I’m going to have one of those days when I just shut down...Those are the Ritalin days (P2).” Such fatigue makes it “harder to work (P2),” especially when work requires much travel.

Many participants had neurological impairments causing various difficulties with chewing, feeding themselves, functional tasks - “I’ve lost a lot of feeling in my...right arm...when I’m picking up my pills from my pillbox, I have to watch them, because my fingers don’t feel it anymore (P3),” or other limitations:
“If I’m out, invariably somebody says ‘oh shall I cut that for you?’ and I have to say ‘yes’ because for me to try to cut, hold the steak and cut it, would be very sort of messy...anything that required the dexterity of two hands.... I don’t have the same [sexual] drive that I used to have...and even if there was, the physical ability would be impaired....When you go through the day and everything you have to be careful of what you do, at the end of the day, if you want to think about going out with someone, ...at the end of they day you’ve expended so much mental effort... you would be burned out. …I’ve noticed I have fallen over...three times, and each time it was because I was not concentrating (P14).”

Pain was another impairment that affected activities: “It’s getting so that it’s much harder for me to walk even a little bit (P21)”; “my back pain...affects my sleep, which tends to slow me down...makes it harder for me to remember things (P23)”; “pain...sometimes gets in the way of sleeping (P10).” Participants found ways to cope with discomfort: “I found distraction a huge remedy for the pain. If I’m doing something I enjoy I don’t think about it (P6)”; “it hurts to start walking, but one of the things I learned on that course, 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).” In fact, one of our potential participants withdrew from enrolment because of pain. Pain appears to be a barrier to good adjustment in SCI (Stensman 1994; Boschen et al. 2003).
Other physical health concerns were reported, including secondary problems: “It’s [heart] accommodated me and I accommodate it (P9)”; “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).” For some participants, the physical conditions they live with become part of their identity – “I don’t think of the [disease] (P16).” For others, they still wish they could do some things they have had to give up – “I’ve gone so long not being able to do that stuff, that if I could, I’d do it, just ‘cause I could (P10).”

Several participants reported being unable to mobilize without necessary orthoses, such as orthopedic or raised shoes, splints, and braces: “Without splints, my ankles would collapse, under the weight of my legs, so it’s pretty uncomfortable (P10)”; “the brace…I’ve never taken a step without it in 15 years…there’s just severe pain (P13).” Physical ability also determines the types of devices that would help in completing activities. A discussion of the impact of devices is found in a later section.

Because management of health conditions contributes to overall physical abilities, we include them in this concept. One participant’s spouse complained about the lack of inexpensive facilities for maintenance, or preventive management. Sometimes, simple measures were found to be helpful - “I have a suppository…because I was only going once a week…I was having accidents (P16)”; “they call them briefs…without them I’d be
“I have to discipline myself and say it’s a lot easier in a wheelchair [laughing] so get yourself out and walk, and don’t lose what you have…but without the wheelchair, I just wouldn’t be able to function….I make myself walk, just to walk, but it’s not practical to get through the day (P2)”;

“If I didn’t have the ventilator, I’d be sort of just tired and sleepy all the time…I just wouldn’t be able to function at all… I wouldn’t be living….It’s pushed my teeth out of alignment, so that’s affected my ability to chew properly (P10)”;

“You GOTTA use it aggressively…everybody just thumping and pounding, and he knows it has to be done…so we’re doing stacked breathing every day at least twice (caregiver of P10).”

Treatments sometimes had their own drawbacks - “I haven’t traveled...where can I go from mid Saturday afternoon ‘til Tuesday morning (P17)?” In this case, treatment schedules interfered with the participant’s ability to participate in some activities.

Participants recognized that as others age, they too must deal with declining abilities:
“I’ve modified my exercise routine, which has reduced my back pain, which has improved my mobility… I’ve also modified my diet again. I find that as I get older in time, I have to keep modifying things, just to stay where I was before…. I see a lot of people my age… going downhill much faster than I think I am… their abilities; my ability to actually perform tasks is just about what it was 30 years ago (P23).”

Another participant also mentioned this about her spouse –

“I have deteriorated a lot. But he’s got a bad back now, so he’s starting to know what some of this immobility, in trying to get his own socks on. We try to joke about it and say well, we’ll get matching wheelchairs, … and we’ll hire somebody to come in and put our socks on in the morning (P13).”

Aging with a disability is a reality that participants have to live through:

“If you try to pack too much in the day… you can feel it… going out in the evenings is not a particularly good idea... I think a lot of it is age… it’s a gradually decreasing amount of energy as you age…. In your old age, the previous injuries come back…. I think one of the things is memory… unless I keep doing this thing over and over again, by the next time I come back to it, I’m almost starting from square one (P19)”;}
“I feel badly when I can’t do something. I think I’m getting to the age now where I can say ‘I’m sorry’ and let it go at that....they know very well I can’t do anything very much anymore. I still have my barriers trailing on me...my barriers, my incapacities (P8).”

These findings concur with those of Stensman (1994) in an SCI population, who found that with increasing age there is a loss of energy and more difficulty in adjusting to changes in life.

**Physical impairments relate to accessibility limitations**

The greater the physical impairment, the greater the accessibility barriers one faces in a non-universally designed environment. Someone who is able to negotiate stairs and curbs can generally access more places than someone who is unable to do so – “I can’t go anywhere where you have to climb stairs (P11).” Others were challenged by terrain:

“I go 2 kilometers down the road, and then 2 kilometers back...especially ...if it’s bumpy, then you have to...tilt it back...which means your arm is...trying to hold it up...my shoulder...hurts...if I’m driving like this, and I sneeze...my arm will flop...if I hit a bump...my arm will go off, and I’ll put it back on, but the wheelchair doesn’t stop (P24).”
Experiences may influence activities/participation

Some participants related disabilities not as due to illness, but derived from past experiences related to social context. For example, a participant reported childhood trauma and abuse that continues to cause her to feel anxious and nervous in middle age, sometimes requiring alleviating medications- “I had a bad childhood…it’s embarrassing you know, so I might back off from something...even the nicest phone call (P3).” This participant’s spouse, in a separate interview, raised this as a barrier as well.

Another example of previous experience affecting current activities was described by a participant who lived through a war, whose home is open to under-privileged single women seeking education:

“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...people who’ve had six years like that, we’re a different breed ... That was one thing - you shared, you were good, most people were good. You got to know the importance of friends...We had a saying ‘there are no atheists in the battlefield.’...We grew up very poor and people were always very good to us (P19).”

For many, aging affected types of activities partaken of - “they’re all dying off...or they’re in nursing homes, and that’s hard for me to go visit (P11).” Previous experiences may temper current ones, such as in travel. “We did a lot of traveling and I’ve good
memories of those, and sit at home now and think about them (P11).” Sometimes, the home is so comfortable that one has no desire to travel, given the “aggravation...I’d just as soon be home (P6).”

Though disability related experiences are discussed throughout this paper, in this section, we demonstrate that certain choices of activities and participation may be influenced by current roles, or personal experiences with disability. As with the general population, current roles influence activities for many - “it’s a lot of sacrifices: financial, family life...I can’t always be there for grandma’s birthday, or my nephew’s birthday, because you have to train (P12)” described an athlete. Another participant described a lot of work related travel. Participants described engaging in educational efforts for lay persons, or trying to help other persons with disability, as a result of their own disability experiences - “I quite often re-arrange things at work to make it easier for them [people with disabilities], because I’m aware of how difficult it is to get something done (P13).”

From the following quotations, one gains insight into reasons for these activities:

“I live a different life than you do, so I know my world...There’s not one day that I’ve [not] come across something that’s not accessible...we had a conference on disability, so I chaired that for a number of years....We have a child with cerebral palsy coming...how do we accommodate her...to show the gifts that people with
disabilities have?...Otherwise, I probably wouldn’t be as interested in helping. I wouldn’t see that person when I went shopping (P12); and

“There were so many things that weren’t accessible...I talked to my family doctor and I said ‘Am I the only disabled person in this community?’ and he said ‘No,’ but he said ‘you’d be the one to maybe try to get something together, like a group.’ ...Once we got the group together I knew right then I wasn’t alone....We tried to involve our families...We were...trying to better the community that we lived in....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, whether or not there’s an elevator, if you can walk up the stairs, ...unless you’re actually experiencing that?...It was an awareness program (P15).”

This participant offered described feeling isolated, such as in sports activities at school—“my job was to sit on the ground and keep score...I’ve always KNOWN that I was different (P15),” and offered a window into childhood experience of disability:

“I wouldn’t say anything to my parents. I wouldn’t tell them...if I was struggling or anything like that... As a child, do you go up to your parent and say ‘you know, kids are teasing me at school?’ ...I tried to pretend that everything was ok....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).”

Benefits of the collective efforts of groups was clear - “we had people that required accessible housing. ...We formed ...the housing board; we had to do a feasibility study to prove that there was a need for a building (P15).” This group was to become successful in effecting accessible housing for persons with disabilities in the community. Organizers of groups took on personal toll, however. Two participants reported fatigue after many years of running support groups, requiring reprieve- “I’m just tired out (caregiver of P10).”

Individual attributes may be influenced by previous experiences

As is the case with many people, participants described previous experiences as influencing their personal outlook, both positively- “confidence...discovering that my brain hadn’t really atrophied as much as I’d thought it had...That was the most fabulous, exciting, intellectual experience I’ve had...opened up all sorts of doors (P5),” and negatively- “I’m afraid to try it...I had a very bad fall (P11).” 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’, ‘humility’, ‘simplicity’, and developing ‘positive contacts.’ They reported ‘positive personality change,’ and ‘less stress.’

Some of our participants described previous experiences as influencing their attitudes towards certain aspects of living, such as cleanliness - “it’s partly a hangover from spending some time in the military (P14),” and

“It was either sink or swim. I had made up my mind as a teenager that anything that they said I couldn’t do or if I heard whispers, I would not only do it, but I would try to do it better than someone else....I guess throughout my lifetime...I’ve always had the feeling I had to prove myself...maybe to myself....I didn’t want people to think that because I had a disability...that my children were not as clean or not as looked after...so my children were super clean; my house had to be really clean (P15).”

Personal experiences with individual physical abilities seemed to influence behaviour in some circumstances. As the caregiver of one participant described, “he can’t shout and jump up and down, and slam a door, so he uses his mouth...that was his way to make his needs known...acting out in class (caregiver of P10).” Another told of physical limitations influencing the decision to stop working:

“It got to the point where I realized, from one day to the next, I couldn’t guarantee him that I would show up...I just turned around and said, ‘Now, it’s
time.’ ... I was doing the right thing, not only for me but for the company. The time had come (P4).”

Individual attributes influence activities and participation

The most influential aspect of individual attributes seemed to be personality, including determination and motivation. “Oh my determination to just keep going is HUGE (P4).”

This participant also described another aspect of personality influencing activities:

“They had their first computer a year after I left...and all of a sudden, everybody was talking about their ‘mouse’...I lost...track of the conversation. What the heck is a mouse? ...So I thought, ‘Oh, that’s gotta change. We’ve gotta get with the program here.’ So I went out and bought myself a computer, and taught myself how to get on the Internet...God forbid I should miss something.”

‘Self-efficacy’ is a term used to describe a person’s belief in his ability to deal effectively with their environment (Bandura 1989). Examples of such self-motivation and positive attitudes abound: “I took the approach that if I’m gonna get anywhere,...I have to do it better...than the able-bodied person...I feel it’s a good attitude to have (P23)”; “I figure as long as I believe in myself that I will do whatever I aspire to (P15)”; and

“Your attitude to it has a big deal to do with things...when I go for a walk, the most difficult part is getting out of my own driveway, because I can think of a
thousand other things I’ve got to do...yet once I’m out there, I feel really
good...the other important thing in my life is my faith. That’s number one, I would
think, because it affects everything I do all day, and my relationship to everyone
else...my faith determines the sort of hope and feelings I have about life... I’m
determined if I’ve only got a short time to live, to live it well (P19).”

Many participants described themselves as independent-minded. According to the
literature, independence should not be judged by competence, but rather by control and
choice in aspects such as risk taking, privacy, and decision making (Rock 1988).
Important aspects of independence include ‘perceived control’, with the expectation of
being able to make decisions, through control over one’s abilities, emotions, and
behaviour, and over human and physical environmental factors (Nosek and Fuhrer 1992).
Nosek and Fuhrer (1992) also described ‘psychological self-reliance’ as an aspect of
independence, including autonomy, integrity, self-assurance, and decision-making. They
imply that self-reliant individuals are stable emotionally, and able to function with little
group support. This may be true, but in our population, participants claiming to be
independent-minded also recognized the value of peer support, and were often
instrumental in organizing such groups.

One beneficial resource that many participants appreciated was time – “having the time
to...sit and TALK to everybody, and get everything straightened out - that certainly
makes it easier (P4).” They talked about helping others – “I try to motivate people to look ...at solving the problem rather than complaining about what happened (P23).”

They also described overall attitudes necessary to meet the social climate experienced by persons with disabilities - “you HAVE to be an advocate (P2).”

Participants discussed 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...the only access would be stairs...I’ll be darned if I’ll be carried up (P11).” They talked about effecting change: “I phoned the city, and I complained. Then I e-mailed a complaint...and about 3 weeks later, I got an e-mail saying if you go that way again, you will find that it is now fixed (P3).” One participant had the initiative to find out how to get hand controls, and learn how to drive. Another discussed a situation where self-advocacy was necessary – “there again it was supposed to be a room for disabled...and it was not. ...My niece and I sat down with the manager and said ‘Look, these things are not good enough (P21).’ ”

Naturally, personal interests determined chosen activities in many instances. Many discussed sending donations to charities as a form of helping others. “The woman who does my income tax always tells me that... I ought to cut back on my charities. ...That’s one of the greatest pleasures of life. ...I mean money in the bank, what’s that? (P19)”
Some talked about not wanting to influence the activities of others because of accessibility issues:

“I would just bow out of something just so that nobody has to do it for me…you don’t know what it’s like ‘til you get there. I don’t wanna get there and have them not do something that they plan to do because I can’t go (P13).”

Some activities depend upon aptitude and skill - “I can tell someone how to build one [computer] if they’re willing to do the physical work (P10).” Education is one thing that some participants credited for the ability to find work- “I’ve spent many years using Auto-CAD… I can use a computer with 95% dexterity (P14) and the education makes a big difference (P2).”

Fears were also expressed, and influenced levels of current activity - “I’d be too afraid [to travel alone]…if my car broke down, anything along the highway (P15),” and

“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. You know? Go ‘til I drop, and then I’ll have to stop (P13).”

Supports assist activities and participation

Despite the obvious limitations caused by physical impairments, physical ability alone does not necessarily determine activities and participation. Several of the most active
community-minded participants had the greatest impairments, requiring significant levels of assistance. They were able to achieve reported levels of participation due to their stated ability to adapt and engage appropriate supports. House (1981) identified different types of support—instrumental and practical support, emotional support, and informational or guidance support. In this section, we discuss five general concepts that we found to be frequent sources of support—organizational systems, including rehabilitation teams which provide instrumental, practical and informational support; relationships, which provide emotional 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 of the environment. It is appropriately subdivided into legislation, which exerts influence at the societal as well as personal level, and other more local programs and regulations, relevant only at the individual level. The important influence of legislation has been mentioned, and participants indicated positive effects of the Ontario Disability Act (ODA) on physical accessibility. “*The ODA came into effect; ... there’ve been a tremendous number of improvements (P2).*” Several were aware of the impact of disability legislation in the United States—“*they’ve got a big piece of legislation over their heads, you know, The Americans with Disabilities Act (ADA). They really know how. They have to treat people right or they’re in hot water....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). Reasonable accommodations include physical access, adjusting training procedures, accommodating or providing assistive devices, modified work schedules, flexible leave policies, moving to part-time status, negotiated time for medical appointments, and staff support (Steinberg 2002).

Legislation is overarching, and may influence social context, accessibility, and availability of supports. However, limitations of legislation were also acknowledged. “For newer buildings…there’s a big difference, but a lot of older places still aren’t…maybe a lot of the smaller businesses…don’t…have the room to put a ramp in, I don’t know (P10).” One participant suggested that “the city could go beyond and develop a whole policy of their own, and maybe they will. Maybe they need to be pushed in that direction (P6),” indicating possibly influencing policy making. Another beneficial piece of legislation is one that bans smoking indoors at public places. “Smoking is a BIG issue....He gets short of breath...we’ve got to change the whole system of filters on his ventilator....Since the no smoking thing, it’s opened up a lot of places for him (caregiver of P10).” Legislation, such as shown in these two examples, can support the well-being of the population. Another participant reported perceived inequities in tax rules, complaining about the inability to claim taxi fare if one does not drive or own a vehicle. “Everybody who lives more than 40 clicks from the hospital can claim taxes. ...They can claim mileage (P17).” Sometimes, rules prove to be disincentives – “in some cases the
laws are such that...if they get off welfare and work, they don’t make as much (P17).”

This participant acknowledged that often, people try to find loopholes around existing rules. “There’s no rule that...has been invented or put in force that somebody is not going to find their way around.”

Participants pointed out disincentives in disability insurance policies:

“There’s a funny quirk in the disability pension, that if I didn’t access it...it would have been less advantageous than if I chose to go off this year, or five years from now...It’s an infuriating policy. I can’t earn a dime. I can’t look for contract work. I can’t offer to be available to do something extra. Their rules are absolutely rigid. At the very least, they would deduct penny for penny what I earned from what they would pay (P5).”

Regulations surrounding travel were also sometimes perceived as barriers – “the restrictions with the flying...I don’t think I could do it. You know you have to be there 3 hours before a trip (P11).” Sometimes, current policies were felt to be a step backwards compared with previous ones. For example, one participant discussed former license plates with handicap symbols as being better than the present system of disabled parking permits - “wheelchair stickers can be abused (caregiver of P3),” reporting better courtesy levels from other drivers with the old system.
At a more individual level, organized programs and health professionals that participants worked with were often helpful. One participant pointed to the recreational therapist as being most enlightening in opening up possible adapted activities. Generally though, health professionals play a small role in the overall lives of participants. Although rehabilitation services were felt to be beneficial, respondents in the report by Boschen et al. (2003) indicated the rehabilitation process was inadequate, particularly with respect to supporting emotional recovery; rehabilitation services and resources were not considered top facilitators. These authors suggested that success of the integration requires support providers who provide information regarding available services and resources, in a timely manner. They also stated that information, services, and resources need to be available at multiple times and in multiple ways, and felt that transition and outpatient services should be expanded. However, 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 et al. 1999). The following are some instances of beneficial health professional interventions reported by our participants:

“I found that course [self-management] very helpful, so I’ve got that I do manage (P19)”;

“He [rehabilitation physician] said... ‘unless you have a walk-in shower stall...you’re not going to be able to get in and out of a tub’... so he gave me the
name and number of a company...this was a whole new learning experience...of what was out there, what was available (P4)”; and

“We’ve been able, for the first time 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).”

Home support programs such as the Community Care Access Centre, – “I have accessed through them a physiotherapist, an occupational therapist, nutritionist...they’re really good (P9)” - and those provided by the Veteran’s Affairs Canada, are sources of health professional support in the home setting. However, not all encounters were beneficial, as the following example shows: “He concluded that...I was a hopeless situation; ...he wrote a dreadful...assessment of my capabilities, my potential (P20).” As a result of such assessment, this participant, who went on to have an illustrious career, had a difficult time initially getting funding approval to complete college studies.

Other organized programs were reported to be helpful in providing assistance with self care and necessary daily activities to support independent living in the community – “if it weren’t for DVA [Department of Veteran’s Affairs], I wouldn’t be alive (P20)”; “Outreach has been phenomenal for me...through the government; ... helps me with...things that I no longer can do...it keeps my independence (P4).” Such programs
were appreciated: “The Ontario Direct Funding program...allows me to be independent (P10)”; “The self directed attendant care...is one of THE most important things in our family life. If we didn’t have that program, I wouldn’t have been able to work. ...It makes it so we have a life, and HE has a life too. You know, we need to get away by ourselves, but HE needs to get away from US....I went through a stage...where I couldn’t walk to do the grocery shopping...and he said ‘I’ll do the shopping’...We have our own van...and his attendants go out with him (caregiver of P10)”;

“The most important thing is my homecare people that come to me...to dress me in the morning, and bathe me. ...They allow me...to stay in my home...I would have to go into a nursing home [without them]...I don’t know how long I can stay here...it depends on the homecare. ...The more people that you can keep...in the home, the happier they will be. There’s no doubt about that in my mind (P21).”

Participants pointed out the rules that restrict access to such programs – “they’re very particular, they only give an hour....I have a friend that will come and help me...a friend or my family (P19).” One participant’s tub lift supported independence in bathing, but limited access to home assistance – “by the same thing I can’t get homemakers because
that’s the stalemate. You can’t get a homemaker unless you need personal care. So I can wash myself, or I can bathe myself…but I never felt clean (P8).”

Some participants arrange or pay for their own programs, such as in retirement homes. However, in some cases, rules of retirement homes serve to keep spouses with differing care needs in separate apartments, where staying together in the same room “would not be possible in our case (P20).” Sometimes, such regulations are untenable for people. “I had a rod put on just outside the bathroom door…they won’t install them for you; they said they don’t want to be sued. ...There have been people move out of here... didn’t like the regimentation (P22).”

Organized activities may include special camps, mentioned by the caregiver of one participant. “It made him a lot more confident in himself...taught them how to live on their own, how to manage their money, how to shop, how to look after an apartment...they taught them how to cook (caregiver of P10).” However, such programs may change over time – “they won’t take people who have really complex issues now...they’re so conscious of injury and lawsuits, and legalities (caregiver of P10).”

Available services were also discussed, such as the “medical supply store - they at least know what the heck they’re talking about (P4).” According to another participant, “suppliers are...a constant source of frustration.” However, this participant also admitted that some service providers were very helpful – “there was not delay...he came
in and he put them on….I have never, ever, called somebody, and they say ‘well, I’ll come to the house tomorrow’ (P10 caregiver).” Other examples of helpful services are described: “I would REALLY like to be able to do them [housework]...we have a lady come in now (P9)”; “I call a barber and he comes in to the apartment (P14)”; and “when I had hurt my knee, and I couldn’t get to the hairdressers, she actually came here and did it for me (P15).” Not surprisingly, participants also benefited from services available to the general public, such as “the library…it’s VERY important. They do so many research things for me (P20).” Another beneficial general service is the postal service, allowing participants to communicate with others, and contribute to charities.

Transportation is a form of access, and may be perceived a barrier or facilitator, depending on availability

Difficulties with public forms of transportation were common. “Buses are just not accessible.... Trains are really awkward...the train stops for five minutes...you have to PAY for VIA 1 (P2),” or first class carriage. One participant spoke of previous experience using accessible public buses in a former place of residence, and how the inaccessible system of the present setting was a barrier to finding work.

“I was on the regular bus when I was going to work, church, whatever.... I can’t use the city bus right now....You need to be...able to get on the bus, get in position, the driver puts a few ties down, bus comes up, and off you go, so it’s not consuming too much time, therefore slowing down the process. ... I won’t be
turning down a job because I can’t get a ride everyday...if I can wheel to work, that would be great (P12).”

This participant saw the local transportation situation as a definite barrier. When using the accessible bus service in this community, “planning is key ... I’ve had to train my family - that if they want to see me, book 2 weeks in advance [laughing]. Save that day, and I’ll phone the bus, and book it (P16).”

People reported differences in train and air travel, experiencing particular difficulties with air travel:

“The policy of VIA Rail makes the travel...easy...; [An airline] dropped the portable scooter and smashed it...and they make no break financially. They don’t make too many accommodations for the disabled, so I notice that VERY distinct difference between train and air travel (P5); and

“I was in a wheelchair, and they guy took me up to the...escalator...he said...
‘You have to take that escalator.’ ...I almost fell. ...When I reached the bottom I was very, very weak....We did get abandoned...you have to wait, of course, until everyone else goes, and we waited and waited, because the attendant knew I needed help....It didn’t come....I had to practically fight for a...wheelchair, ...because people that didn’t ask for one took them (P9).”
Potential solutions were also offered – “there’s just one thing I was thinking about these airports... I think it should be the other way around; I think they should let the disabled person go out first and have a wheelchair at the top of the entrance way, and THEN let the other people (caregiver of P9).” Another participant was made to feel that “in the airport, apparently if you’re in a wheelchair, you’re... trying to smuggle in drugs; ...we did not have fun at the airport (P24).”

Purchasable services such as taxis were appreciated – “if they weren’t there, I don’t know what I would do (P14).” However, some negative experiences were reported with respect to the attitudes of some taxi drivers-

“a lot of them won’t pick up at the grocery store... because there’s groceries to carry.... They all have heart problems; they can’t lift up the wheelchair...sometimes I wait a little longer and they’d say ‘nobody wanted to take it,’ but I’ve always got a ride. They said point blank ‘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).” Private transportation allowed some participants to continue living in their location of choice. “[Without the van] I think...
I’d have to move, which would make me very sad (P5).” Some spoke of difficulties finding suitable vehicles – “cars have become smaller...I’ve always had a bench seat. The newer cars have...bucket seats and stick shift (P15).” Benefits of having one’s own vehicle included helping others “by lending them the van (P1),” driving others, or being able to

“pick up ... friends who are in wheelchairs and take them places...I can go wherever I want as long as I have a driver...finding a driver is a lot easier than trying to find an access bus, because they’re so limited (P24).”

Even if they did have private transportation, some required assistance to manage folding wheelchairs and store them in the trunk – “I can’t get it in and out myself...My trunk’s up too high to lift it (P13).” Some features on vehicles were helpful – “I’ve got a sliding door on my driver’s side now (P23)”; “I’m looking at getting a lift...for my truck to make it easier to get into (P6).” Another owned a van “that is converted” and hired drivers. “The person that’s here drives me everywhere. ...I’ve been told I can’t drive,...not allowed to drive (P21).” Some people voluntarily gave up this form of transportation, taking on more restrictions in activity choices -

“I sold my car the day before I moved in here, so I’m relying ...on...where they take us....If I have a medical appointment, I say right away ‘I live in a retirement home; we have a bus that takes us out on Tuesdays; other than that, I’ll have to get a taxi.’...I don’t go where I want to go; I go where the bus takes us (P22).”
Lack of private transportation was felt to be a barrier for certain activities such as volunteering – “they’d have to pick me up (P17).” When traveling, “if I don’t bring my own transportation, then FINDING transportation is really hard (P24).” Sometimes, participants are able to secure transportation through others. “Once people know how easy it [transporting the wheelchair] is, they’re more willing to include you in activities (P12).”

Relationships as supports

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. Many participants credited the people they were close to as being supportive. We discuss the reported contributions of spouses, family, friends, and others.

In a spousal relationship, “you really have to see what is best for both (P9),” when it comes to decision making. “Throughout our whole marriage...I had the sense of normalcy...we worked as a team (P15).” This bond sometimes continued even after death – “he asked me what I was going to do after he died (P19).” The appreciation people had for their spouses was evident: “Not everybody has a wife that can do what mine does (P23); “I would have a VERY different lifestyle if I had to live on my own. I would have to move into an apartment. I would have to make different arrangements for shopping, transportation, everything (P2).” Flanagan (1982) reported a gender
difference in important close relationships that were reported, namely that for men, the spouse was very important, while women, particularly older women, depended more on children and female friends for support. It is possible that this is a reflection of the demographics and differing life expectancy for women and men, and perhaps a reflection of reality rather than a true difference in support preference. No such differences were obvious in the interviews of our married participants.

When it comes to finding a spouse when one has a disability, one participant said

“I’m pretty sure that people look at people with disabilities differently than a person that’s able to walk and able to go to the park with them...Because if you have to get a wheelchair in and out all the time to take somebody, I think it would have a big impact (P13).”

Another participant pointed out physical drawbacks that may come into consideration – “what’s sexy about...let me take off your diaper? (P24)”

Assistance from family was important to children with disabilities. “My family is awesome at finding ways for me to do everything. ...It doesn’t really feel like the accident happened because...nobody has changed (P24).” Their parents stressed the importance of their own attitudes in encouraging their children’s independence. Also, as do parents in general, parents with disabilities spoke of adjusting their activities to those of “the
children…those years from…12 … ’til they’re driving…that’s tough. We’d go to games, to practices, just to sit there (P13).”

Parents with disabilities appreciated assistance from their children. “We’ve always had this…friendship with the kids…. Without my family, I wouldn’t function (P8).” Often, children held powers of attorney. Sometimes, children lived rather far away – “I have a wonderful son…but he’s 3000 miles away (P21).” Often, parents were reluctant to impose upon their children:

“Independent spirit, I suppose… my family, I don’t want them doing anything for me that I can do for myself, even if it means struggling with it. …I might…live to be over 100. If you start now helping me all the time,…you’re going to be wishing I was dead by the time I’m 100…Kids…have a life of their own, right?...I mean, most people would do it, but they’d get tired of doing it (P19).”

Siblings were often close – “just her presence often is enough of a motivator that even if I feel crappy, get out of bed and have a shower and clean up around the house…I’d never do it but there is that quiet temptation to pretend I’ve got a relapse just so she’ll come down (P5).” “It’s important to have family around that help (P19).” However, sometimes, the extended family may not always be as helpful, or else, people might not wish to impose: “Now they see me as less. So they shelter me…I know they mean well, but it just really annoys me sometimes [laughing] (P3)”; “I have nieces and nephews,
but I don’t like asking them to take me things. I do sometimes if it’s necessary...take me shopping (P22); “family attitudes can affect what you do and how you do things, and how much you SEE the family (P10 caregiver).”

Friendships were also appreciated, and recognized as important. Many participants experienced the loss of friends after becoming disabled: “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); “a lot of friends deserted (P17).” Sometimes, participants themselves consciously extricated themselves from certain friendships – “it makes them feel awkward, so I have deliberately phased out...those friendships...there comes a time in your life when you have to sort of back out (P14).” However, even for this person the importance of developing new friendships prevailed – “people are...one of the reasons for living. The more people you meet the richer your life is.” One participant thought that being in a wheelchair actually facilitated meeting nice people: “I have not had any...bad experiences because I’m in a wheelchair, and I certainly haven’t lacked from meeting new people because I’m in a wheelchair. If anything, I’m actually talking to MORE people (P4).” As one ages though, one may not be able to see one’s aging friends as often – “my friends are...having problems too now (P21).” Friends and acquaintances may provide useful advice – “people around me...recommended that I consider these things and I think that’s very wise counsel, and I just wish I’d listened to it longer ago (P6).”
If family or friends help with activities, their schedules need to be taken into account—“each time I go I have someone else coming with me. So it’s all got to be scheduled around other people’s schedules (P15).” Sometimes, assistance is provided by others, such as with travel—“if it’s organized ... there’ll be people there who can help me...that’s why those trips are enjoyable...I’d never go on my own (P19).” Assistance from others may come at additional cost that may deter one from visiting others—“you have to have somebody go with you to everything, and either stay with you or go back home and come back and get you...it’s just not the same...financial drain too, because you have to pay the person to wait for you (P21).”

Peer support was reported to be helpful by some:

“I phone another fellow...talk back and forth. He’s been very helpful as far as some suggestions are concerned.... That’s what we desperately need, is a group of people that are experiencing somewhat the same things, to be able to help and suggest...it’d really save a lot, not only finances, but also surgeries and different things...just to make choices (P9).”

Coping and adapting to physical disability may involve learning from others facing similar challenges. “My husband talked to a lady coming out of the hardware store,... ‘do you mind if I watch how you,... because my wife has [a disability] (P13).’”

In a retirement residence, one suddenly has a whole community of peers, who might look out for each other—“if somebody had said ‘I’m not feeling very well today’ at noon, and
then they didn’t show up for supper...you could call the office and say ‘I wonder if ___’s ok’, you know, so they’d go and check (P22).” Drawbacks were also reported - “in a place like this, you have nothing to do except talk...and by the time it gets to the 10th person, it’s something different (P22).” One participant had strong views on the need to maintain friendships and acquaintances as one ages:

“I don’t think a retirement home should be allowed to be built unless there’s a nursing home that’s attached to it... and if you’re mobile at all, you can get back to see Mrs. X....They’ve already made friends in the retirement home, and now you’re all on your own again...it’s criminal...Changing from retirement home to a nursing home when one or the other becomes incapacitated...I’m sure you make more in a retirement home than you do in a nursing home...if I were putting money anywhere, I would put it into a retirement home, naturally, but I don’t think you should be allowed to do that, because your bid’s just being cruel to people (P21).”

Some participants acknowledged support from their employers as being important in their continuing gainful employment. 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. Several employers were actually pro-active in their support: “My boss told me... ‘I will never ever tell you “you have to leave.”’ So he was the one that let me have that job for as long as I wanted (P4);
“luckily my place of employment…they’ve allowed me to park there….So as I couldn’t do one thing, they created another…flexibility I guess (P13)”; “the person that hired me had a disability…spoon-fed me that job, because she knew…I had the capability. I didn’t have any self confidence back then (P12)”; “he said, ‘for graduate work, we’re interested in you, if you can get back’…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) urged those in leadership roles to have open communication with employees with disabilities ‘recognizing the legitimate fears of disclosure.’ As in our examples above, critical mentors were thought to be important. These authors indicate that leaders should be aware that persons with disability may fear requesting accommodations such as modified work schedules, flexible leave policies, moving to part-time status, negotiated time for medical appointments, assistive technologies, and additional staff support.

DeJong and Hughes (1982) looked at ranking and weighting of living arrangement outcomes by members of an interagency council on independent living. There appeared to be preferences in living situation. In rank order, these are: 1) living with a spouse, “significant other” or minor children, living alone, or living with friends/siblings; 2) living with parents and spouse/children, or living with other relatives; and 3) living in an institution, though their results may be biased due to their respondent pool, who were likely advocates of independent living. Our study did not explore preferred living situations, though several participants indicated a preference to remain in their own homes as long as possible rather than in an institution.
Devices usually facilitate activities

One important mobility device used by many participants is the wheelchair: “My wheelchair – I’d be lost without it. The wheelchair is literally my little world, because my little world goes with me (P4)”; “I wouldn’t be going past my doorstep really (P15).” For some, “it’s my only means of transportation (P16).” Sometimes, the wheelchair becomes incorporated into one’s identity – “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)”; and “I go for a nice long walk, about 4 km, just for some fresh air (P3)” - this participant evidently considered the scooter an extension of the body. The following quotation also describes how the wheelchair may become an extension of oneself, as well as facilitating optimal activity levels:

“You know when you step up on a curb…sometimes, you’re gonna misjudge that, and you’re gonna stumble…same thing in a chair. And our stairs are curb cuts…the odd time, you misjudge…and you end up flipping onto the pavement….If it’s 99% positive…Without the chair, I’d be in bed all the time, but that’s no way to live….and I’d probably lose strength, lose muscle. I’d probably be in a long term care facility (P12).”

Even for someone who is able to ambulate, albeit with difficulty, “the wheelchair’s the biggest thing, because it gives me the most freedom.” Without it, “I’d be pretty much restricted to being in the house…half the time, I’m crawling….I can’t do anything
without the chair (P23).” Some see having the wheelchair as an advantage - “I’m amazed at what I can do in a wheelchair, absolutely amazed. First of all, you have to walk, you have to carry things. And I can sling them on my back here (P20).” One participant even told of her friends envying her chair, as her activity tolerance for shopping was extended beyond theirs because of the wheels. However, one participant who was able to ambulate, found decreased independence with a wheelchair, because of impaired arm function – “when you’re in a wheelchair, you have to wait for somebody to push you (P21).”

Accessories for wheelchairs can also be important – “the chairlift on my power chair has really taken...the stress of my arms completely (P9).” Reid (2003, p.193) reported the wheelchair as being described as ‘my liberator, my sense of comfort’.

It is important that wheelchair specifications be individualized: “This wheelchair doesn’t provide adequate support...Once I get my new chair, and maybe get proper seating and support, I don’t think it would be as big a problem...(P10); and “I’ve had these wheelchairs...you borrow, and they’re up like this, and they hurt my shoulders. With my own custom made one, as long as my arms are down here, it doesn’t hurt my shoulders. And my arms don’t tire (P13).” Nevertheless, sometimes people may be reluctant to take this step:

“I’m really looking forward to getting my wheelchair...once my legs get tired, at least I can still get around you know, and take the wash to the bedroom, even if it’s on my lap and I go in a wheelchair, without getting really angry and
frustrated… It was suggested to me, like 3 years ago, but I said ‘no’…just wasn’t ready (P3).”

Physical access differed according to type of wheelchair used. People who require power mobility for independence, also tended to have access to a manual wheelchair, in order to negotiate less physically accessible places with assistance. Often, the weight of power wheelchairs and scooters, and the associated risks, preclude them from accessing places with steps. As indicated above, many people’s homes are rather inaccessible to wheeled mobility. “If I take my manual chair I can pretty much go anywhere as long as there’s a big man to…pick me up….The [power] chair weighs...400 pounds, and it’s about $17 000, so I don’t want to risk you carrying me up the stairs (P24).” This participant articulated some pros and cons of a manual wheelchair – “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…it’s faster….If I was in my manual chair and I was pushing it…at the end of the day, I’d be…’my shoulders are killing me.’” Participants also preferred friends to transport them to special occasions rather than have their schedules dictated by the schedules and availability of 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).”
Some other devices, such as scooters and golf carts also allow increased access. “I have a little portable. The technology is such that I can take it with me, and collapse it, and put it into the trunk.” For this participant, the scooter was necessary for her well-being, without which, “I’d be mentally housebound. Either a fear in the winter or fatigue in the summer… My world would shrink dramatically (P5).” Another reported “I have a golf cart…that was one of the best things I ever bought….It’s a good way to get on people’s properties that you wouldn’t be able to get on in a wheelchair.” In the winter, “the golf cart goes into storage. It doesn’t have traction (P6).”

Similar sentiments were revealed when it came to 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)” ; and “I’d be sitting in a chair most of the day (P5).” Walkers allow participants to “at least be able to get from one room to another, ” and without mobility aids, “I’d be in bed (P21).” Some people use gait aids for “a slight zone of protection (P3).” Others use different gait aids for different purposes – for example, one participant used crutches for “rough terrain…increasing my range by about 3 times” as compared with canes; this participant used the walker “around the house when my back is really acting up (P23).” Often, gait aids were used in conjunction with prostheses or orthoses for the lower extremities: “I have it [prosthesis] sitting over there…I’ll put it on here and walk outside…cutting the grass…I walk up them [stairs] with the leg, and I need a hand rail. I use the cane…I guess crawling would be the next answer (P17)” and “without the shoes,
I wouldn’t have walked for the last 25 years…it’s built up an inch and a half, and [has]…orthotics in it (P21).”

Grab bars, poles, and other fixed objects assist with independent mobility by providing stability during activities such as toileting, and moving from one surface to another. “The bar is used to…get up to the sitting position and then the raised bed helps me get off (P9).” The pole “gives me balance. It’s something to hang onto (P16).” Along with other devices within the bathroom, such as raised toilet seats, bath lifts, or track lifts - “I put a track lift in…a wonderful device. I can use it independently (P6).” These devices may mean the difference between independence and dependency:

“These are the two things that have really helped me to stay fairly independent. The bath lift, and the bed railing. I can get up, you know, get dressed myself, and get into a tub and wash myself and do all that. That’s made a world of difference…. If I didn’t have the railing,....I could probably do it, but...by the time I made it onto the chair I would be so exhausted, I would wanna go right back to bed again....I think my determination would probably get me there, but at what cost (P4)?”

Some devices allowed other people to help them in their own homes - “I have a mechanical lift…it will pick me up off the bed, take me into the bathroom, it will turn and put me on the toilet (P16).”
Readily available conveniences available to the general population may become necessities for some persons with disabilities, such as electric razors, or kitchen appliances: “Thank God for microwaves, that’s all I can say (P4)”; “I have a dishwasher...very important; I’m always dropping things...cups and glasses (P19)”; “that drafting chair...gives me the ability to go over to the sink to do the dishes, to cut up vegetables and do a whole variety of things, ...within the kitchen (P9).”

Computers, fast becoming a necessity in today’s world, are “a way to connect...I’m sort of enjoying what can emerge via e-mail (P5)”; “we primarily...communicate through the computer (P9).” Computers seemed to be more crucial to those with impairments severely limiting their mobility, and were felt to be essential to some, who used them for arranging travel, shopping, banking, and storing information: “We’ve done a couple of trips that way...right in the convenience of your own home.... The digital cameras are great. Take me a picture; throw it on the screen (P6),” described a participant who was unable to access equipment in the basement, but was able to assist in problem solving through such technology. Computers help people to be independent:

“It helps me do...the book-keeping for the direct funding program...I do the scheduling and the payroll by myself...I do a lot of research on it...a lot of on-line shopping...I do most of my banking on-line too...the most independent I am is when I’m on the computer (P10)” and
“If I don’t have my internet and my computer…I don’t know what to do. I do EVERYTHING on my computer….I spilled a cup of tea on my computer and my computer shut down…I had a little panic attack because…my whole life is on my computer….My computer is…my life; everybody will tell you that…an extra, extra, extra large factor (P24).”

Similarly, the telephone and other emergency communication systems were felt to be important in obtaining help when required. One participant’s view on the call alert system was that “everybody that lives alone should have one (P8).” Another explained why – “the first thing I put on is this Life line thing…it’s a bit like insurance. You don’t think you need it until it happens and then you need it. One day, it might be supreme (P14).”

For those with impaired mobility, the telephone helps maintain connections with friends who live in inaccessible homes – “I’m on the phone all the time too…. I’d visit them in a phone conversation, or I’d make them come to me (P24).”

Other helpful devices were reported, such as environmental controls – “if I wanted to turn the heat down,…then I just use my mouth…it’s hooked up to the door here (P24)”, and portable ramps – “the portable ramp has let me get on…wagon rides…relatives houses (P24).” A few used devices of their own making: “I drew…this tea trolley and had it made up and now…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…it was a bed tray and you took off the sides and put that on....I mentioned what I was having difficulty
with, and he [said] ‘oh, I can fix that’ (P9)”; and “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).”

‘Embodiment’ is the term used for aspects of the person’s environment that are depended upon to complete activities (Reid et al. 2003). Reid et al. found that on average, 11 assistive devices were used by persons with disabilities. They reported a constant need to negotiate and advocate for devices, to meet changing family and functional status. Many examples of embodiment were discussed above, in regards to wheelchairs, walkers, transfer aids, ramps, and even attendant care aides if necessary. We propose that a synonym of this term, ‘embracement,’ be used to describe the phenomenon of an object or device becoming considered an extension of, or even a part of oneself, as described by some participants above. The respondents of Reid et al. also reported devices as representing freedom, and extensions of themselves. Meanings ascribed to ‘embracement’ include the concepts of eager acceptance and inclusion as something broader (American Heritage Dictionary 2006).

Some drawbacks to adaptive equipment were reported.

“It makes traveling a bit more difficult…it’s just a lot of work hauling my commode, and my Hoyer lift, er, all my mattress and bedding and stuff, all that…I generally bring most of my equipment with me…. I have a van as well…a lot of times…we’ve arranged to get…a hospital bed brought to the hotel room....The
only problem...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 as well (P10).”

On the other hand, without equipment such as bed or mattress when traveling, problems might arise – “if I couldn’t sleep, I wouldn’t function that well (P13).” Other equipment is also available for rent during travel – “I rented...a Hoyer lift,...a commode chair... (P24).”

Income is a factor

In many of the above examples, participants alluded to the fact that many activities cost more money for persons with disabilities, due to the need to arrange for equipment, climate control such as air conditioning, assistance, special transportation, or larger rooms: “You can get handicapped rooms in a lot of places, but you know, they charge you...more (P13).” It seems ironic that people who experience a drop in income should bear increased financial burden. “Money – I’m being more careful. I’m now on a disability pension and I’m a little more conscious (P5).” Some were fortunate to have insurance plans: “It’s covered by my insurance...I took a fairly significant drop in my income when I went on disability (P6).”
For some, costs were 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), certain costs, such as those of home modifications, are inexpensive relative to potential benefits. He indicated that approximately 56% of those needing home adaptations are home-owners, and suggested that municipalities consider building codes that ensure that new housing construction is accessible, and to offer grants, loans, or reimbursements to persons with disability to modify existing units. There exist programs in Canada with such intent (Service Canada 2007). We saw from our participants’ experiences that government programs and supportive relationships can reduce reliance on personal income. Personal income or funding programs help participants to obtain devices and other necessary supports to complete their activities.

Sources of income included “Canada Pension disability. It gives a lot of people support…income (P3).” Provincial disability pensions such as Ontario Disability Support Program were also mentioned – “I have some rent that I pay…I’ll buy some groceries…[with] my ODSP pension (P10).” Others had spousal or their own “pension…it’s a large (P9).” “The private insurance one doesn’t go up every year; the CPP goes up every year (P4).” Income was a factor in maintaining independent living – “without my income I couldn’t stay, because I couldn’t expect…the government to provide it all….I have to consider now that it costs me a lot of money to do anything (P21).” 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
when I hit 65. I plan months in advance; 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 many examples provided in the preceding sections demonstrate the importance of adapting to changed and changing situations: “it’s a...forbidding territory...for the person who’s newly injured or someone who’s trying to reinvent themselves....I can remember that like it was yesterday but...I got over that pretty fast (P6)”; and “it’s a mental adjustment, but I think after you do that, you settle down and realize...you’re pretty lucky to do it at all....I’m just very, very thankful for what I am able to do (P21).”

The most immediate adaptations to new physical impairments are generally ones involving new techniques, such as in doing one’s hair, or moving about – “I did learn how to get out of bed...more back friendly fashion ...I find myself...using a strategic spot on the wall to hold onto as I climb into the tub (P5)” ; “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, or other less accessible places - “use the male urinal...you can usually do it discreetly enough...you wouldn’t really know what they’re doing down at their feet.” Adapting takes trial, practise, and perseverance: “He’s willing to try doing things and figure out how he can adapt...he doesn’t do change well
(caregiver of P10)”; “it took about 2 years to do a transfer into a van...confidence, balance, coordination, and strength (P12)” ; and “I’ve become VERY inventive (P4).”

Positive influences on the adaptation process reported in the literature include personality (particularly ‘obstinacy and being positive’), ability to get help, 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). Those respondents also lived in a society with social support systems, and high financial security for persons with disabilities.

Many strategies were reported by our participants in going about their daily activities, because “you wanna be able to do as much as possible with whatever abilities you still have (P4)”; “I’ve had to change my approach to do things (P9)”; “I try to improvise ... I try...to have 6, 7, 8 things in my wheelchair...rather than have to ask somebody to carry this stuff (P13)”;

“the brassiere is a little tricky...I pull it, do the hooks in the front and pull it down...I have to put it on backwards....I like elastic at the waist of my trousers...anything with buttons, I never unbutton them (P8)”;

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“what I’m trying to do now is remember where the curb cuts are... ’cause 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)”; and

“another problem... is shopping for clothing, because you can’t go in the changing room when you try stuff on, so you have to... bring it back and then try it on... the only thing I can try out in places are big sweaters and shoes (P24).”

Participants found more convenient ways of doing things – “I do a lot of stuff by mail... contributions to different societies or causes (P11).” When shopping, “I have to plan more.... I would... go by myself to a store where I know I can park close, use the crutches, and not spend a lot of time (P2).” Some shopped on-line – “I do some shopping on there... I buy most of my clothes that way. Even if I go to the mall, I don’t have the stamina to sit down and try on clothing.... There’s quite a few grocery stores that deliver too... we just found that on the Internet (P3)”; and “if you try, there’s a way. A lot of people in my position, you find, are able to work miracles at getting around a problem (P14)”

Pacing is often required, and involves recognition of one’s physical limitations, and taking them into account when planning activities: “I also know my limitations; I’ve
learned that if you were going to overdo it, you’re going to pay for it the very next day (P4)”; “it’s HOW I travel, and taking extra days (P2)”; and

“I am now taking longer to do my self care and that seems to pay off in that by pacing myself through the day and resting when I need to, not having to engage in too many forced activities, I seem to be able to get through the day, not that I am more energetic, but I am not as profoundly fatigued…. I’ll think a few days ahead strategically (P5).”

Over and over again, the theme of needing to plan around all activities arose: “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)”; and “you have to think ahead…it’s a planning ahead thing…You just have to schedule things more than somebody else might. And then the equipment (P6).” Participants planned for winter, and they planned extensively for trips: “We went on a cruise…there’s a lot of planning ahead (P4)”; “dig all the information and double check. When you ask if it’s wheelchair accessible, they say ‘oh yeah’ but it may not be…there are different definitions of wheelchair accessibility (P12)”; “I plan ahead…I had to find out if the winery was going to be accessible, if the room were, if getting to the tent where the meal was gonna be, if I could get there. I had to…plan everything all ahead to know that I could do it before I went (P13)”; and “when you travel, you have to accommodate the wheelchair…you always have to phone ahead…traveling is more expensive because you sort of have to work around it (P23).”
One also has to adapt to the attitudes of others in society. Personality and personal approach helped participants adjust to the social situations they faced – “can’t be lonely if you like who you are...I’m comfortable with myself.... If someone’s got an attitude, no I don’t have the time of day for that, so I just walk away (P12).”

Successful adaptation depends somewhat on individual attributes, experiences, and ability to engage available supports. Adaptation is also a learning process, as one participant acknowledged – “I probably haven’t been as smart as I could have been as far as looking at alternative assistance. Getting help…this latest experience has made me realize that...I’ve gotta overcome that resistance.... ‘Think smarter not harder’, that’s my new motto (P6).” After awhile, one learns to “integrate...a lot of different [things] without even probably knowing (P15).” Another reported “you learn to be very bold in asking for things (caregiver of P10).” When assessing someone’s ability to assist, one participant said

“people, they look at you, and they think...you’re going to crumble. ...If people aren’t comfortable, if they haven’t dealt a lot with disability, or physically dealt with picking someone up or carrying them...I don’t push...I don’t like to be lifted unless I have to be (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 et al. (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, modified techniques, problem-solving, acceptance, asserting oneself with family, using home adaptations, mobility aids, and adaptive equipment for independence and enhanced functioning; ‘retaining a sense of personal control is an important feature of adaptation.’ Boschen et al. (2003) indicated that strategies of ‘retooling’, ‘reframing’, and ‘rearranging’ were used when adapting to new impairments.

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)” ; “there’s no point; you can’t make these things problems. It would be nothing BUT a problem if you...just kept worrying about it (P21)” ; and “I’ve just come to terms with the limitations I have now ... I have no desire to prove anything to anybody anymore...there was a bit of that, proving oneself 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 1-2 years post-injury, as compared with those with SCI for longer durations.

**Factors affecting activities and participation**

We present evidence from the literature that supports our findings, in the process of building a model. 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 were generally affected by personal interests, abilities, necessity, physical accessibility and home modifications, while roles resulted 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 (eg. job description), mesosystemic (eg. factors necessary to do work, supports), and macrosystemic (eg.access to labour market, legislation, universal design). Fougeyrollas et al. (2002) argues that if there were a clear, internationally accepted conceptual model indicating that disadvantage is caused not by paralysis but by environmental factors, insurers could be in a position to claim
compensation from organizations responsible for such environmental barriers. The model we present below could possibility be used for such an argument.

Factors affecting community integration 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. (2003) asked participants to indicate how important items were to them in fifteen 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 in a spinal cord injured population, 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 in the literature include supports such as provision of information related to disability, health stability; adequate income, including disability insurance programs; advocacy, self-help, and peer counseling; 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; familiar communities; 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; job opportunities and training; and personality, or personal motivation
(Boschen 1994; Boschen and Gargaro 1998; Boschen et al. 2003; McColl and Skinner
1995; Dunn 1990; Noreau et al. 2002). Similar facilitators were reported by our
participants, who described interrelationships between such facilitators and their activities
and participation. Other 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 counseling and employment services as 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 and
supplies/equipment; chronic pain and other health complications causing poorer health
status; negative attitudes of others (Noreau et al. 2002; Boschen et al. 2003). 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
what the barriers to such activities were in that population. If one understands the
barriers to restricted activities, perhaps appropriate rectification or supports might be put
into place.

Summary of conceptual relationships

From the descriptions and relationships provided above, 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 (WHO 2001) and the human development model of the disability creation process (Fougeyrollas et al. 2002), which arose out of the conceptual model of the handicap creation process (Fougeyrollas et al. 1998, p. 130), 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 (2002) simply shows personal factors and environmental factors interacting with life habits, defined as daily activities or social roles valued by the person (p.8); they include health conditions within personal factors. Despite arguments of Fougeyrollas et al. (2002) 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,’ (p.1) but considering scenarios such as environmental factors leading to secondary impairments (p.11), 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 state, needs, knowledge, beliefs, attitudes, capacities, learner, preferences, and self-concept. The concept of ‘environment’ includes physical, policy, opportunities, forces, context, social and cultural milieu (p. 77).

Bronfenbrenner’s Ecological Systems Model (1977) presents concentric circles progressing from the microsystem individual level, to the mesosystem family, work, or school level, to the exosystem social structural level, to the macrosystem 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

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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. Again, its relationships are quite general. Other models which try to detail the process of adaptation more also exist, showing various interactions between person and environment (Jackson and Schkade 2000). Our study sought to look primarily at what factors affected activities and participation, and their relationships. Another type of model format is found in the circular Occupational Performance Process Model, with various stages in the process of resolving issues (Fearing et al. 1997).

The Successful Adaptation Model

In Figure 2, we present a model that includes the 8 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. 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 is more appropriately situated with other concepts that affect the larger community, such as weather, social context, and physical accessibility. The proposed model does assume 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 personal factors that inter-relate. Our sample was comprised of volunteers, and it is possible that the relative importance of personal factors may be biased because of this. 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. They themselves may in turn exert reciprocal effects on one or more factors. For example, the actions of a person with disability may lead to changes in attitudes of others, or physical accessibility of a location. Others, too, have grouped these two concepts (Voorman 2006, Jette 2005), which demonstrate particular overlap in some areas of life, such as economic and domestic life (Gandek 2007). Differentiating ‘activity’ from ‘participation’ remains a topic of investigation (Jette 2003).
**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)
Weather

Individual Attributes

Experiences

Physical ability

Adapting

Supports (5 types)

Physical Accessibility

Social context

legislation (Supports-organizational)

Integrity

Activities Participation

change

restoration

additional or progressive condition
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, rehabilitation professionals could foster positive attitudes encouraged by our participants, facilitate additional education if required, and provide appropriate and relevant counseling to persons with disability. 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 support people in their adjustment to personal 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 effected 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.

Acknowledgements

The authors would like to acknowledge the Southeastern Ontario Academic Medical Association and Clinical Teachers Association at Queen’s University for funding this research. Also, thanks to Queen’s University Inter-professional Patient-Centred Education Direction for a small stipend. This paper constitutes a portion of the thesis of Joy Wee, for the degree of Master of Science. Finally, we thank our participants, and close with a quotation from one – “I think what’s really important is people giving you a chance...You open your eyes, open your mind, and then open your heart.”
**References**


Chapter 4

Reporting of Factors affecting Activities and Participation in Persons with Disability in Rehabilitation Measures

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Reporting of Factors affecting Activities and Participation in Persons with Disability in Rehabilitation Measures

Joy Wee, MD, FRCPC, Rosemary Lysaght, PhD

Abstract

Purpose- This paper describes important factors affecting the activities and participation of persons with disabilities, and recommends templates for inclusion of contextual information with standard measures of activities and participation.

Method- This mixed methods study employed grounded theory approaches, data conversion techniques, and quantification of the projected impact of factors on standard measures. Semi-structured interviews of participants with disabilities living in the community for at least 1 year were conducted to identify factors impacting upon activities and participation, and the magnitude of their influence. Each participant was scored on both the Barthel Index (BI) and the Participation Scale (P-scale). BI scores that would be obtained without the contributory facilitating factors were estimated. Estimation of the impact of identified factors on the BI and P-scale was conducted per participant, and scores averaged amongst all participants. Large influential factors were incorporated into reporting tools for each of these measures.

Results- 24 participants identified 258 factors. For the BI, adaptive equipment, gait aids, wheelchairs and scooters, and home modifications were most contributory. For the P-
scale, personality, community and home accessibility, level of impairment, mobility aids such as wheelchairs and scooters, and transportation were among the most influential factors.

**Conclusion** - Based on convergent results of various methods of identifying important factors, accompanying reporting schemes are suggested for contextual factors, in conjunction with standardized measures of activities and participation.

**Introduction**

Communication amongst health professionals across international settings has been steadily increasing, with a general trend towards globalization emerging in almost all aspects of life. Our global setting presents many different environments, physically and culturally. Amongst health professionals working with persons with disabilities, there is a push to standardize how one measures of functional ability, community participation, and quality of life across the world, for better comparability and communication. However, in some settings, beneficial equipment for maximizing functional ability may be unavailable or unaffordable, or there may exist different cultural practices as concern daily activities (Wee 2006). Other factors, such as age (Alander et al. 1997; Liem et al. 2004), community or home accessibility (Noreau et al. 2002), or rurality, may impact upon measures of activities and participation. Rural residents have been reported to experience such barriers as lack of public transportation, limited health providers, distance, and low income (Morgan 2005; Rosswurm 2001). In order to better interpret scores obtained on
such measures, it would be helpful to know the impact of such factors and how they might affect scores. The purpose of this study was to determine the main factors that influence function from the point of view of persons with disabilities, and how these factors might be reported along with outcome measures. Two research questions addressed in this paper include:

1) **What factors do persons with medically stable disability feel influence their activities and participation?**

2) **How can reporting of important factors be incorporated in a useful manner, in conjunction with standard tools measuring activities and participation?**

As a tool to assist exploration of factors affecting activities of daily living (ADLs), the well known and tested Barthel Index (BI) was used. This tool was developed and tested in populations with various diagnoses: stroke, spinal cord injury, other neurologic conditions, arthritis, burns, cardiac problems, amputations, and the elderly (Canadian Physiotherapy Assn 2002). In cognitively intact persons, the BI as a self-report measure was found to be highly reliable (Valach et al. 2003). In a study measuring activities and participation in a spinal cord injury population, the original BI was found to be as useful, or better, than the Modified BI (Wee and Schwarz 2004). The developers of the BI identified factors such as grab bars and doorway widths that could potentially influence scores (Mahoney and Barthel 1965), and recommended that an explanation of special
environmental requirements accompany the BI. However, this has not become standard practice amongst health professionals.

We used the Participation Scale (P-scale, van Brakel et al. 2006) to guide inquiry into factors that affect participation. This scale acknowledges that personal factors are important; its scoring system includes a rating by each individual as to how important any given activity is. Authors of the P-scale indicate that criterion and concurrent validity, reliability, and stability were checked in Brazil, India, and Nepal by the original test development team, and that its face validity was further demonstrated in several diagnostic groups. A previous study suggested access to public funding, transportation, equipment, and accommodations as contributory factors to scores (Wee and Schwarz 2004).

**Methods**

Participants requiring the use of mobility aids were purposefully selected from the Kingston, Ontario region. Kingston is a mid-sized city that serves as a tertiary referral centre for surrounding rural areas. Participants were recruited from the patient population of the primary author, as well as through advertisements in the community newspaper. Purposive theoretical sampling (Maxwell 1997) was used to maximize range of impairment type, severity, and demographic characteristics, including rural and urban residents. Rural residence was defined in our study as residences that did not receive municipal water supply, sewer, or waste removal services. Each eligible participant
received a letter of information and signed a consent form. Interviews occurred at mutually agreeable times and places. Ethical approval for this study was obtained through the Queen’s University and Providence Continuing Care Centre (now Providence Care) Research Ethics Boards.

Participants identified factors that affect their activities and participation generally, and then more specifically, by answering questions concerning current function, and perceived effect of the identified factors on functional performance. Interviews started out with a global open question “in the past year or longer, what factors have you found to affect your activities in and outside the home?” They then proceeded of both open- and closed-ended questions based on categories within the BI and P-scale (Creswell 2003). Closed-ended questions were used to guide data conversion (i.e. ranking of importance of reported factors). Since data were obtained through interviews, relying upon individuals’ memory and self awareness, each participant was required to undergo a screening mental status examination (Folstein et al. 1975) to ensure they were functioning in the normal range, defined as 27/30 or higher. Following the interviews, factors identified by each participant as influencing activities and participation were listed and mailed to them for ranking of the top 10. This procedure is a form of member-checking, or verification.

Interviews were audio-recorded and transcribed verbatim. Data were analyzed for themes and repeated patterns. Recurring themes were identified with respect to factors that affect
ADLs and participation. For a detailed account of the grounded theory analysis methods used, see Wee and Paterson (2007). Each participant was individually scored on the two measures, according to self-report, and these scores were compared against observations made by the primary author.

Data conversion (Caracelli and Greene 1993) was used to convert descriptors of factor impact into numerical values, based on reports by participants: ‘No impact’ was given a numerical value of 0, ‘small’ impact, 1, ‘medium’ impact, 2, ‘large’ impact, 3, and any description larger than ‘large’, 4. Each factor’s reported impact on each BI or P-scale category was determined per participant, by applying the numeric value of the absence or presence of the factor on each category. For example, if one were to consider a cane, in the BI, it may affect transfers, toilet transfers, walking, and stair climbing. For the P-scale categories, it may affect accessing common places in the community, visiting people, travel, helping others, etc. Therefore, if a participant reported a cane as being a small factor with respect to transfers, it was assigned a score of 1 for that domain, while if it was reported as a large factor for stair climbing, it was assigned a score of 3 for that activity. Through this process, the reported impact of each factor on each domain was scored, and could be averaged across all participants, to obtain a numeric result.

The overall impact of factors on each scale was then determined. For the BI, the numeric influence of each applicable factor was tallied numerically for all categories of the scale, according to the above rating process. Additionally, for the BI, change scores were
gleaned from the information provided by participants, and estimations were made of the BI scores they would have obtained without the reported factors. As an example, for the toileting category on the BI, a participant requiring a raised toilet seat for independent toilet transfers would score 5 or 10 points lower without this piece of equipment, depending on the individual’s impairment severity. Resultant change scores for each factor on each category were tallied to yield an overall effect on each participant’s BI score. Both numeric impact of factors and change scores were averaged across all 24 participants to obtain numeric values per factor, and rank ordered.

For the P-scale, many more factors were reported as having impact in each category. The numeric impact of each individual factor was similarly tallied through data conversion, for each category of the scale, and summed per participant. However, because scoring on the P-scale depends on importance of specific activities to the individual, we did not attempt to estimate actual change scores. One of the factors, namely personality, could not be assigned scores as to the impact on each domain. Therefore, for the P-scale, only the summed numeric impact of factors per participant was averaged for all 24 participants, and rank ordered.

**Results**

Twenty-four participants were selected with the following demographic information:
Mean age, 63.5 years (range 20 years to 93 years); modal and median ages were both 60 years. There were 9 male and 15 female participants. Diagnostic groupings were as follows: 4 participants had muscular dystrophy or myopathy, 3 had acquired brain injury, 5 had multiple sclerosis, 4 had poliomyelitis, 3 had spinal cord injury, and 5 had miscellaneous orthopedic conditions, including arthritis and amputation. Twelve were married, 8 single, and 8 widowed. Two were employed full-time, 2 part-time, 5 were unemployed (1 was a student), and 15 retired. Income was in the low bracket for 11, mid-range for 9, high bracket for 1, and undeclared for 3. Two lived in retirement homes, 6 in multifamily complexes, and the remainder in single family homes. Three lived in an urban setting, 14 in a residential suburban setting, and 7 in rural settings.

Figure 1 depicts actual BI and P-Scale scores for each participant. Guidelines have been proposed regarding interpretation of these scores, and are indicated with the Figure (van Brackel et al. 2006; Shah et al. 1989). Observations of the primary author, a practising rehabilitation medicine specialist, and participant’s self-reports of independence were compared with actual BI scores. The observations revealed 4 participants who were completely dependent in care needs, requiring assistance for mobility, even in bed. The average BI score for this group, with all facilitators in place, was 31.3. Three participants required moderate to major assistance, with average BI score of 58.3. Seven required minor assistance, with average BI score of 85.7, and 10 were independent for self care, with average BI score of 92.
Figure 1. Barthel Index and Participant Scale scores of all 24 participants

Scale y-axis: each line represents a score of 20

Interpretation of:

**BI scores** 0-20 total dependence, 21-60 severe dependence, 61-90 moderate dependence, 91-99 slight dependence, 100 independent, according to Shah et al. (1989)

**P-scale scores** 53-90 extreme restriction, 33-52 severe restriction, 23-32 moderate restriction, 13-22 mild restriction, 0-12 no significant restriction (van Brakel 2006)
Through grounded theory methods as described by Wee and Paterson (2007), the qualitative data from transcripts were analyzed and summarized. Fifty-nine factors were identified with the first open question used, and with the more specific questions guided by domains of the BI and P-scale, 258 factors were identified by participants. Open and selective coding led to factors being grouped into the following concepts: personal attributes, physical accessibility, supports, weather, physical ability, experiences, and social context. The ‘supports’ concept was further subdivided into the following types: relationships, transportation, income, systemic or organizational, and devices. Table 1 lists, in order of reported frequency, the factors being identified as ‘large’ in impact from the open ended questioning portion of the interview. On the right are the concepts these factors lie within. Member checking and listing of the top 10 led to the results in Table 2.

Results from the more detailed questions, and data conversion identified 15 reported factors affecting the BI, shown in Table 3, which reports averaged numeric impact and change scores for the BI. Table 4 lists the most influential factors on the P-scale. Averaged P-scale numeric impact ranged from 0.1 (traffic light timing) to 14.2 (personality, interests, motivation), with a mean of 4.2. Mean values were 0.96 for numeric impact, and -1.9 for change scores of factors affecting the BI. Figure 2 depicts actual BI scores and resultant projected change in BI scores per participant, without current facilitative factors. Mean BI score with facilitators was 76, while that without
facilitators was 54, representing a substantial change in score of 20 or higher, which based on interpretation by Shah et al. (1989), would mean a drop in level of independence without facilitating factors. Adaptive aids led to changes in participant designations, from 4 totally dependent, 8 severely dependent, 11 moderately dependent, and 1 independent, to 4 severely dependent, 11 moderately dependent, 5 mildly dependent, and 3 independent. Observing scores shown in Figure 2, BI scores did not appear to correlate with P-scale scores.

Though this study was not designed to assess factors through statistical analysis, we did examine whether 7 individuals living in rural areas seemed to have different levels of participation in the community, by matching them with participants of similar BI scores living in residential or urban areas. P-scale scores of 10.6 ± 5.4 were obtained for the subgroup of participants living in rural locations, while the matched group scored an average P-scale score of 11.9 ± 6.4, no better than the rural subgroup (average BI=75 for both groups). Participants had not identified rural living as a barrier, but rather a personal choice and seemed to have adjusted their chosen activities accordingly. Similarly, we could not adequately look at educational level quantitatively, though several participants indicated that it was important. The average BI score for the subgroup of 4 with secondary education was the same as for the subgroup of 6 with postgraduate education.
Table 1

*Factors identified as large by participants in response to question “in the past year, what factors have you noticed affect your activities inside and outside the home?”*

<table>
<thead>
<tr>
<th>Factor reported</th>
<th>Concept</th>
<th>Number of Participants</th>
<th>Rank order</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impairment</td>
<td>Physical Ability</td>
<td>22</td>
<td>1</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Physical Accessibility</td>
<td>19</td>
<td>2</td>
</tr>
<tr>
<td>Personality</td>
<td>Individual Attributes</td>
<td>16</td>
<td>3</td>
</tr>
<tr>
<td>Wheelchair</td>
<td>Supports-devices</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>Equipment in home</td>
<td>Supports-devices</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Transportation</td>
<td>Supports-transportation</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Family</td>
<td>Supports-relationships</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Income</td>
<td>Supports-income</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Gait aids</td>
<td>Supports-devices</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Home accessibility</td>
<td>Physical Accessibility</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Weather</td>
<td>Weather</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>
Table 2

Factors ranked by participants in the top 10 of those identified in response to the same question as in Table 1

<table>
<thead>
<tr>
<th>Factor reported</th>
<th>Concept</th>
<th>Number of Participants</th>
<th>Rank order</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality</td>
<td>Individual Attributes</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>Transportation</td>
<td>Supports-transportation</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Equipment in home</td>
<td>Supports- devices</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Physical Accessibility</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Impairment</td>
<td>Physical Ability</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Home accessibility</td>
<td>Accessibility</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Income</td>
<td>Supports- income</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Wheelchair</td>
<td>Supports- devices</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Family</td>
<td>Supports- relationships</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Weather</td>
<td>Weather</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Gait aids</td>
<td>Supports- devices</td>
<td>6</td>
<td>11</td>
</tr>
</tbody>
</table>
Table 3

*Impact of all reported factors on Barthel Index with summed numeric impact and change scores shown, averaged across 24 participants*

<table>
<thead>
<tr>
<th>Factor reported</th>
<th>Averaged numeric impact</th>
<th>Averaged change score</th>
<th>Concept</th>
<th>Rank Order</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive devices</td>
<td>4.2</td>
<td>-7.5</td>
<td>Supports- devices</td>
<td>1</td>
</tr>
<tr>
<td>Gait aid ± prosthesis/orthosis</td>
<td>2.2</td>
<td>-6.5</td>
<td>Supports- devices</td>
<td>2</td>
</tr>
<tr>
<td>Adaptive fixtures</td>
<td>1.6</td>
<td>-2.5</td>
<td>Supports- devices</td>
<td>3</td>
</tr>
<tr>
<td>Manual wheelchair</td>
<td>1.4</td>
<td>-2.1</td>
<td>Supports- devices</td>
<td>4</td>
</tr>
<tr>
<td>Railing</td>
<td>1.3</td>
<td>-2.5</td>
<td>Physical Accessibility</td>
<td>5</td>
</tr>
<tr>
<td>Power mobility</td>
<td>1.2</td>
<td>-1.5</td>
<td>Supports- devices</td>
<td>6</td>
</tr>
<tr>
<td>Home renovations</td>
<td>0.5</td>
<td>-1.1</td>
<td>Physical Accessibility</td>
<td>7</td>
</tr>
<tr>
<td>Food consistency</td>
<td>0.4</td>
<td>-1.5</td>
<td>Physical ability</td>
<td>8</td>
</tr>
<tr>
<td>Ventilator</td>
<td>0.4</td>
<td>-0.4</td>
<td>Physical ability</td>
<td>9</td>
</tr>
<tr>
<td>Fatigue</td>
<td>0.3</td>
<td>-0.1</td>
<td>Physical ability</td>
<td>10</td>
</tr>
<tr>
<td>Medications</td>
<td>0.3</td>
<td>-0.6</td>
<td>Physical ability</td>
<td>11</td>
</tr>
<tr>
<td>Spasms/pain</td>
<td>0.3</td>
<td>-0.6</td>
<td>Physical ability</td>
<td>12</td>
</tr>
<tr>
<td>Bowel routine</td>
<td>0.3</td>
<td>-0.4</td>
<td>Physical ability</td>
<td>13</td>
</tr>
<tr>
<td>Incontinence pad</td>
<td>0.1</td>
<td>-0.4</td>
<td>Supports- devices</td>
<td>14</td>
</tr>
</tbody>
</table>
Table 4

*Most influential factors on Participation Scale as reported by participants, with averaged summed impact shown*

<table>
<thead>
<tr>
<th>Factor reported</th>
<th>Averaged numeric Impact</th>
<th>Concept</th>
<th>Rank Order</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personality</td>
<td>14.2</td>
<td>Individual Attributes</td>
<td>1</td>
</tr>
<tr>
<td>Accessibility</td>
<td>13.4</td>
<td>Physical Accessibility</td>
<td>2</td>
</tr>
<tr>
<td>Impairment</td>
<td>12.2</td>
<td>Physical Ability</td>
<td>3</td>
</tr>
<tr>
<td>Wheeled mobility</td>
<td>11</td>
<td>Supports- devices</td>
<td>4</td>
</tr>
<tr>
<td>Transportation</td>
<td>8.3</td>
<td>Transportation</td>
<td>5</td>
</tr>
<tr>
<td>Income</td>
<td>8</td>
<td>Supports- income</td>
<td>6</td>
</tr>
<tr>
<td>Services</td>
<td>6.4</td>
<td>Supports- systemic</td>
<td>7</td>
</tr>
<tr>
<td>Family/friends</td>
<td>5.5</td>
<td>Supports- relationships</td>
<td>8</td>
</tr>
<tr>
<td>Circumstance</td>
<td>5</td>
<td>Experiences</td>
<td>9</td>
</tr>
<tr>
<td>Systems</td>
<td>4.7</td>
<td>Supports- systemic</td>
<td>10</td>
</tr>
<tr>
<td>Adaptive equipment</td>
<td>4.2</td>
<td>Supports- devices</td>
<td>11</td>
</tr>
</tbody>
</table>
Figure 2. Change in Barthel Index scores without facilitative factors
Actual BI scores (purple) and projected BI scores without facilitative factors (blue)
Data are clustered for diagnoses, in order of Muscular Dystrophy, Orthopedic diagnoses,
Acquired Brain Injury, Multiple Sclerosis, Spinal Cord Injury, and Poliomyelitis.
P-scale scores were higher in the former (12.8 ± 2.8 as compared with 7.2 ± 3.8). In participants for whom we had information about income, there existed a relationship between educational level and income on average, with income bracket reported as being higher for those with higher levels of education.

When grouping reported factors according to the concepts determined through our qualitative analysis, it became clear that devices seemed to be the most important factor, taking into account all methods of triangulation that we employed. Physical accessibility was the next most important. Importance seemed to vary depending on what type of activity was being considered. For activities of daily living (as measured through the BI) the following factors had the greatest impact on performance: adaptive devices, home adaptations (environmental factors), and physical ability (body structures and function).

Of the 24 participants, 14 required bedrails, bars or fixed poles; 12 required seats for bathing, 4 reporting mechanized lifts into the bathtub; and 11 required raised toilet seats or commodes. Other devices were less frequently reported. For participation in the community (as measured by the P-scale), individual attributes (personal factors) play a large role. Physical accessibility and physical ability were also high in rank. After these, seemed to come various types of environmental factors: transportation, income, systemic regulations and organized programs, and personal relationships. Based on this analysis, and combining results shown in Figure 1 and Tables 1 through 4, we present the following templates to be used along with the BI and P-scale (Figures 3 and 4).
**Figure 3. Template for the Barthel Index**

**Diagnosis:** ______________________ (stable/active)          **Date:** __________

<table>
<thead>
<tr>
<th>Factor</th>
<th>Specify requirement (or N/A)</th>
<th>Obtained (Y/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheeled mobility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gait aid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other adaptive device(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- grab bars/ bedrail/pole</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- raised toilet seat/commode</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- bath lift/shower/bath seat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- orthosis/prosthesis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- other device:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home adaptations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- railing(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- bathroom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Figure 4. Template for the Participation scale

**Diagnosis:** __________________________ (stable/active)  
**Date:** ____________

<table>
<thead>
<tr>
<th>ICF category</th>
<th>Description</th>
<th>Existing Y/N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal factors</td>
<td>Motivated community participant</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other (specify)</td>
<td></td>
</tr>
<tr>
<td>Environmental factors</td>
<td>Accessible community (list limitations)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Accessible home</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wheelchair/gait aid (circle, describe)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other beneficial equipment (specify)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appropriate transportation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Services and Programs (describe)</td>
<td></td>
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<td>Supports (family/friends/neighbours)</td>
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<td>Other (specify)</td>
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**Discussion**

It is reassuring to see that our use of specific categories in the standardized measures to guide interview questions led to identification of approximately 200 more factors than provided in response to the first, open ended, global question. The global question would presumably identify the factors that stand out in each participant’s mind, but when further questioning occurred, other systemic supports, such as disability pensions, government assisted home care, and attendant care funding programs emerged as important factors. These are perhaps more hidden, but important in facilitating activities and participation in the community for persons with disabilities.

Though participants reported physical ability as an important factor in all the methods used, disability level, as reflected by BI scores, did not seem clearly related to participation, as reflected by P-scale scores, as shown in Figure 1. Though BI scores ranged from severe disability to complete independence, the majority of participants were found to report no significant restriction in participation (17 of 24). This finding is supported by another report of impairment and other demographic features not having significant influence on community integration in a spinal cord injury population (Norris 2000). Participation is therefore more influenced by the other factors reported by participants.

Another observation we made is that in this population of persons with varied causes of disability, the guidelines provided by Shah for interpreting BI scores (1989), developed
for a stroke rehabilitation population, do not seem to agree with reports by, and observations of, our participants. This suggests that future studies to further develop guidelines for interpreting the level of required assistance on BI scores may be warranted for different diagnostic populations of persons with disabilities, since this measure remains in frequent use throughout the world.

One factor that might have been expected to impact upon participants is the location of their homes. It has been suggested that people living in rural areas have less access to services, because of distance, limited transportation, and similar disadvantages (Morgan 2005; Rosswurm 2001). There are many ways to define the term ‘rural’ (Whiteneck et al. 1999); it can be defined according to population density (census takers often use this definition Blazer et al. 1995; Burge et al. 2005), location, roots, or way of life, and has intrinsic diversity (towns, villages, urban satellite areas, farm, non-farm, and remote areas - Hart et al. 2005; Havens et al. 2001). Some countries have developed sophisticated systems to measure ‘remoteness’ and ‘rurality’ (Hart et al. 2005; Commonwealth Department of Health and Aged Care 2005; Ocana-Riola et al. 2005). No such system has been developed in Canada. Some define ‘rurality’ as a continuum (Rosswurm 2001). The need for studies of abilities of rural persons to perform activities has been identified (Havens et al. 2001). Our study population did not reveal apparent differences in P-scale scores based on rural residence. However, in order to adequately address this issue, a larger, quantitative study would be required.
We have reported factors that affect activities and participation in a population of persons with varying causes of disability. A Canadian population was purposely selected because of the supportive social system in existence in Canada, with the hope that most participants would have had opportunity to explore and experience a wealth of beneficial factors with the guidance of health professionals, in support of their activities. From this relatively endowed society, it was felt that major facilitators could be identified, rather than conducting the study in a population with limited access to many beneficial factors such as governmental supports and legislation, accessible venues, accessible transportation, devices, and the like. On the other hand, it is possible that some factors may differ from other settings. For example, in Canada, winters were reported as a large barrier by many participants during the portion of the calendar year that is affected; this may not be the case in areas with more temperate climates. In other settings, additional barriers may exist (Wee October 2006).

Our findings are in agreement with those of other studies. A spinal cord injured (SCI) population indicated facilitators of social participation to include home accessibility, relationships, available services, public disability insurance, and assistive devices (Noreau et al. 2002). Obstacles reported included weather, available employment, accessibility of other’s residences, and the time required to complete tasks. One study found that individuals with disability reported spending more time in the community once barriers were removed in their homes (Dunn 1990). Another reported predictors of independent living to include income, functional ability, number of medications, locus of
control, social support, access to transportation, and home accessibility. This report also listed beneficial assistive devices in descending order to include manual wheelchair, lift, power wheelchair, modified eating utensils, walker, cane, crutches (Boschen 1994), which would be covered in the templates we provide. Our study suggests that educational level might be a factor to consider for further study.

Participants in our study were living in the community, including residential home settings. We did not include participants living in nursing home settings. This is a limitation of our study. We did not obtain information from persons who might be, according to Shah, ‘totally dependent’ for activities of daily living. However, several of our participants required total assistance, even to move in bed. They were able to live in the community due to insurance, or government support programs available to those able to direct their own care. Presumably, those living in nursing home settings were not able to access such supports, and would not be able to contribute much to information about facilitators of activities and participation to include with the BI and P-scale. However, they might be able to shed light on some barriers.

Participants in this study supported the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) concept that “functioning and disability is…a dynamic interaction between health conditions…and contextual factors…both personal and environmental factors” (WHO 2001). Our recommended templates consider the contextual classification used in the ICF. Though there has been
some discussion in the literature about linking the ICF to health indices or scales, it had not generally been in the context of enhancing them (Cieza et al. 2002).

Reducing multidimensional factors’ influence on activities and participation to numbers, as scales often do, is not without inherent difficulties. However, they are helpful in some ways. For example, in Canada, we have national reporting systems which incorporate scales into the data collected from each participating institution. These lead to generation of comparative data, or benchmarks, that each institution may use to assess itself against other institutions. Useful information regarding contextual differences between sites can be obtained through the use of the templates suggested above. One participant commented on methods for studying a topic: “The take-home message that I got was sample, sample, sample, sample to get reliability. A whole bunch of different ways, a whole bunch of different times…and the tool has to be flexible.” We trust that the templates are flexible enough yet contain information to help health professionals interpret not only the numeric values, but the contexts surrounding scores on these outcome measures.

As there are no other proposed standardized formats of reporting contextual factors in the literature we suggest, as a start, that the above templates be used when reporting individual BI and P-scale scores, attached as additional information, for mobility impaired persons in settings similar to the one described. The outcome measures themselves are not to be altered, as they have been validated as they are. Templates are
simply to be attached to each completed measure of an individual’s activity or participation. This can allow one to have a fuller picture when clinically following someone long-term. When grouped information is required, numbers of factors ‘required’ can be compared with numbers ‘obtained’ or ‘existing,’ and reported with group scores. In this manner, one may ascertain at a glance whether two populations being compared have similar contextual characteristics, and whether such comparison is valid. This contextual information may also guide further intervention, at the individual, group, or societal level.

Since these templates were developed through a population protected by a Charter of Human Rights and Responsibilities, the templates would likely need to be further modified for international comparisons, to include other environmental factors, such as high levels of discrimination against groups of persons based on certain characteristics (Wee October 2006). Further study using these methods in other disability groups and other settings is required to further define which important factors should be reported, in the effort to refine assessment tools suitable for international comparisons. Future studies using other well-known and validated outcome measures could determine if these templates might also be used with other measures of activities and participation. Also, studies looking at application of such templates would be helpful in determining whether or not they prove to be clinically practical.
Summary

We have provided templates to be used in conjunction with two freely available and validated health outcome measures, the BI and the P-scale. Though these templates could be useful individually to present a more complete picture, by presenting contextual information in addition to a number, they can also be used to see if populations from different settings are indeed comparable with each other. Such information can also be used by policy makers and program planners to guide further interventions within programs or communities, in order to improve the activities and participation of persons with disability.

Acknowledgements

The authors would like to acknowledge the Southeastern Ontario Academic Medical Association and Clinical Teachers Association at Queen’s University for funding this research. Also, thanks to Queen’s University Inter-professional Patient-Centred Education Direction for a student stipend. This paper constitutes a portion of the thesis of Joy Wee, for the degree of Master of Science.
References


Wee J (October 2006) *The Social Dimensions of Human Disability across Global Settings* CCIH/CCGHR 13th Canadian Conference on International Health, Ottawa, ON, peer-reviewed poster abstract


Chapter 5

General Discussion

The ICF outlines various environmental factors that may impact activities and participation, such as products and technology, natural and human-made environment, support and relationships, attitudes, and services, systems, and policies, without indicating importance (WHO 2001, p. 30). In exploring the research questions, one might have considered simply design a questionnaire to ask participants to rate each of these ICF-identified contextual factors in a reductive manner. However, the ICF itself admits underdevelopment of its conceptualization of personal factors, and to take such an approach would involve assuming that environmental factors, rather than personal factors, are most important to participants. In this study, open questions were used to explore which factors stand out in participants’ minds as being important. Through the mixed methodology used, data from the ground up could then be compared with theoretical frameworks such as described by the ICF, rather than letting such frameworks guide data. As it turned out, participants felt that individual attributes were very important factors in influencing their participation.

Few exemplars of mixed methods studies that integrate methods from conception to completion exist in the literature (Bryman 2007). The literature calls for exemplars that explicitly demonstrate practical techniques for combining qualitative and quantitative data (Morgan 1998). The lack of specific rules allows freedom to explore different
techniques (Happ et al. 2006). This mixed method study is an example of how different paradigmic approaches can be combined from the outset, and carried through to result in useful findings. The qualitative approach was essential in determining what to include in the templates intended to improve the utility of outcome measures, which are quantitative tools of measurement. According to Johnson et al. (2007, p. 117), ‘we currently are in a three methodological or research paradigm world, with quantitative, qualitative, and mixed methods research all thriving and co-existing.’

This study demonstrates ‘qualitative-quantitative linkage’ at all three levels described by Miles and Huberman (1994 p.43). The first, ‘quantitizing level’ involved conversion of qualitative information into rankings; the second level which links distinct data types, linked qualitative information from the interview, with numerical data obtained through individual participants’ outcome scores; and the third, overall study design level, by combining qualitative and quantitative approaches of constructivism and post-positivism.

From this study, one gains a fuller picture of how factors affect the activities and participation in persons with disabilities, which can be combined with what is reported in available literature. Many of these factors appear to apply to persons with a broad range of physical impairments that cause mobility impairments. However, this study did not include participants with some types of physical impairments, such as blindness, hearing loss, and other possible causes of disability. Therefore, this study is placed within the
literature concerning persons with mobility restrictions. Presumably, other specific factors designed to improve physical access, such as available Braille signage, and acoustic enhancements would benefit those with blindness and hearing impairment, respectively. Nevertheless, it is likely that factors would still fall within the concepts outlined in the model presented.

There is much discussion in the literature regarding what causes disability, and the models that support these arguments. There are people who approach disability from a medical standpoint, holding that disability must include a state of impairment (Boorse 1977), and those who maintain that disability is caused by society in its lack of accommodations for all citizens (Hahn 1986). Bickenbach et al. (1999) go into great detail about the arguments by various camps, and suggests that an appropriate model for disability should be flexible enough to ‘guide research and data collection in all aspects’ of life for persons with disabilities (p.1176).

The Successful Adaptation Model presented in Chapter 3, Figure 2 (pp. 136, 137) assists with conceptualization of how different factors interact with each other in life, detailing the complexity of their relationships, including changes and adaptations that may occur in time. This model adds detail to other models in the literature, and illustrates an example of change and adaptation to one of the factors, namely physical ability. The concepts of physical ability, individual attributes, adapting or adaptation,
devices, supports, physical accessibility, and weather have all been described in the literature in one way or another. This model more explicitly shows how some personal experiences can influence the activities and roles of a person, taking it out of the individual attributes concept, even though, in time, these experiences ultimately blend into individual attributes. Fougeyrollas et al. (2002) referred to the result of this person-environment development process as ‘personal identity,’ that forms one’s intrinsic attributes. In our population, particularly negative experiences often led to individuals becoming pro-active; perhaps it is the reaction of individuals to these experiences that make them stand out as important factors that should be acknowledged.

The model presented is somewhat closer to the Disability Creation Process model than the ICF, in that physical abilities are included within personal factors. Adapting is also considered a personal factor. The environmental factors in the model include physical accessibility, all types of supports, weather, and social context. It shows the individual interacting with environmental factors and undergoing an adaptation process. Others have also reported the importance of personal development in parallel with external factors in achieving desired activities (Mettavainio and Ahlgren 2004). The Successful Adaptation Model also combines activities and participation, as increasingly, the scientific community is recognizing that these concepts are difficult to separate.
This model does not necessarily point to physical impairment as cause of disability (limitation in activities). With this model, one might envision how social context barriers can solely affect activities and participation. For example, in a society where women are not permitted to undertake certain activities, or assume certain roles, social context is the cause of disability. We have examples of this in our own society, such as with laws regarding driving age and guardianship.

It will be interesting to see the development of definitions such as ‘Accessibility’, which in this manuscript generally refers to passage through physical environments. As indicated in Chapter 3, ‘Transportation’ and ‘Weather’, also relates to ‘Physical Accessibility’ in this study. The word ‘Accessibility’ is changing in its scope of meaning. More and more, this term is being used in the lay arena as meaning facilitation of activities and participation: ‘Accessibility is that which enables people to achieve their full potential in life,’ (Onley 2007) including the presence of role models, assistance, or job offers, in the life experience of persons with disabilities. This evolving quality is an inherent property of language itself.

Risjord et al. (2002) maintained that theories that include both qualitative and quantitative questions and answers would be more complete than theories restricted to single methods. They indicated that if triangulation leads to conflicting results, investigators may wish to discount the theory being investigated. If one combines
complementary findings detailed in Chapters 3 and 4, namely the model presented and the ranking of factors, one might arrive at two more complete theories of factors affecting activities of daily living and participation: One might state that the most important factors affecting activities of daily living in descending order include the environmental factors of devices and home accessibility, and the personal factor of physical ability, after which may come other factors such as individual attributes, experiences, adapting, social context, weather, supports, and other aspects of physical accessibility; for participation, one might state that the most important factors in descending order are individual attributes, physical accessibility, physical ability, supports, and relationships, followed by others, such as social context, weather, experiences, and adapting. One might then conduct additional research to prove or disprove these theories. Before one can declare such theories with certainty, one would have to conduct further quantitative studies that include a much greater number of participants to rank these concepts in order of importance, based on power calculations that account for ability to find statistical significance when combining all factors.

Through interviews, data conversion, application of outcome measures, and member checking regarding the importance of reported factors, an understanding of which factors are the most important was obtained in this population. In the literature, the only papers that tried to analyze relative importance of factors did so through factor analysis of specific factors in narrowly defined populations (DeJong 1982; Boschen and Gargaro 1998, Whiteneck et al. 1999). This work adds to the body of literature on what the most
influential factors might be, from the point of view of persons with mobility impairments themselves. For activities of daily living, adaptive devices (such as fixed bars bath seats or lifts, raised toilet seats and others), home adaptations, and physical ability were found to be most important. Devices, individual attributes, physical accessibility, and physical ability were important in the community activities and roles that people engaged in. This contribution is important, as there are few studies reporting the relative importance of factors that affect activities.

Some might ask how generalizable the findings from this work are. The figure on page 45 indicates that the majority of important common factors were identified by the first ten or so participants, and it seems unlikely that many new large common factors would need to be added to the theory generated through this work as to which factors are the most important in influencing activities and participation in a mobility impaired population. Nevertheless, some logical next steps might be to extend the breadth of demographic characteristics in participants, and perhaps include children and other younger populations, persons from various cultural backgrounds, and from more diverse impairment groups. One must also keep in mind the relatively supportive setting in which this study was conducted. For further insights into factors affecting persons with disabilities in other settings, similar studies should be completed elsewhere, and with different disability populations.
At this time, though the results are sufficiently congruent to state that certain factors are important enough to include in descriptions of functional achievement, such as including them in templates of outcome measures, they are not sufficient to declare rankings or relative values of factors in the form of theory. Still, the reporting of these factors can be useful, and standardization of such reporting should be advocated, such as through the templates recommended in Chapter 4. According to some, ‘information generated from assessment scales is only constructive if the information generated is clinically useful and scientifically reliable (Hartigan 2007, abstract).’ The templates may be used for individual care, and for groups of persons with disabilities, as in a rehabilitation unit, for comparison purposes.

Some may ask why one might need to include templates derived from group data for the purposes of clinical care for individuals, since factors are necessarily individualized. The templates are a useful form of reporting, and have room for additional important factors to be inserted. If one includes the templates along with scores in an individual’s record, one can then refer to it at a later date, for comparison with repeat assessment on the same measure, and at a glance, determine if the context remained similar. For example, if a person with weak hip girdle muscles were not able to transfer independently from a wheelchair, and a month later was re-assessed to be able to transfer because a self-lifting seat was obtained, one would like to easily communicate to another health professional that the resultant change in BI was due primarily to the change in device rather than an improvement in muscle strength. Templates may also be useful in settings where health
care providers are less familiar with facilitative factors, in cuing them to consider potentially beneficial factors in their rehabilitation interventions.

With respect to group settings, these templates may be useful for assessing if aggregate outcome measure scores that compare two different populations of patients, such as what is regularly reported by organizations such as CIHI, are indeed comparable. If they are not comparable, at least knowing major differences in existing contextual factors may provide useful clinical information in order to guide rehabilitation team development or improvement of service delivery. This, in fact, is an effort toward achieving one of the goals outlined as ‘future work’ in the ICF (WHO 2001, p. 251), namely ‘development of assessment instruments for identification and measurement.’ Other future goals identified in the ICF included establishing an international data set and framework to permit international comparisons, development of a Personal Factors component, and research into treatment or intervention matching.(p. 251). This work represents a contributory effort towards these goals.

To return full circle to the rationale for this study stemming from difficulties in comparing outcomes in different world-wide global settings, one now has an understanding of factors in one Canadian setting. With this understanding, particularly of important facilitative factors, one can go on to assess the availability or applicability of these factors in other settings such as in Nepal, as well as additional barriers that may
exist. The need for appropriate and easily documentable global health indicators, both direct and indirect (Larson and Mercer 2004) is necessary for developing a good understanding of the factors affecting activities and participation in so-called ‘developing countries’ as well as more economically endowed countries. One might consider some of these important factors, such as availability and affordability of various supports, as potential candidates for global health indicators.

For a health professional working with other health professionals on interdisciplinary rehabilitation teams, it is important to appreciate what the influential factors are, as well as their relative importance in the lives of persons with disabilities. By understanding such relationships, appropriate interventions can be targeted at appropriate times, no matter which approach of service is used, whether through biomedical rehabilitation, client-centred rehabilitation, community based rehabilitation, or the independent living approach (McColl et al. 1997). If changes are required in inter-professional practice systems, there exist recommendations on how to effect such change (Charles and Glennie 2002). Most importantly, given the relatively brief encounters that rehabilitation personnel have with persons with disabilities, assisting them by maximizing their own awareness of available supports, and strategies for adapting, would be most effective in the long run, in supporting persons with disability to fully engage in activities and roles of their choice. The results of this study may also encourage rehabilitation professionals to offer long-term contact with persons with substantial or progressive physical
disabilities, as many continue to face new challenges as life progresses, and ongoing support and education with each stage of change may be appreciated.
Chapter 6

Summary

This thesis presents a conceptual model that helps to explain inter-relating factors and their relationships with participants’ activities and participation. Important factors have been determined, and templates developed, to be used for including this important contextual information when reporting on outcome measures. This body of work has met its objectives, which were to explore, from the perspectives and experiences of persons with disabilities, the shared factors important to them, to understand relationships between such factors in how they affect activities and participation or roles, and to recommend a method of reporting important common factors in conjunction with outcome measures, so that health professionals working with persons with disability may collaborate and communicate more effectively with one another and the populations they serve.
Reference List for Chapters 1 and 5, General Introduction and General Discussion


Appendix A

QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS RESEARCH ETHICS BOARD

Queen's University in accordance with the "Tri-Council Policy Statement, 1998" prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

Dr. A.F. Clark
Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)

Dr. S. Burke
Emeritus Professor, School of Nursing, Queen's University

Rev. T. Deliac
Community Member

Dr. M. Evans
Community Member

Dr. M. Green
Assistant Professor, Department of Family Medicine, Queen's University

Ms. T.C. Knott
Research & Evaluation, Southeastern Regional Geriatric Program, Providence Continuing Care Centre - St. Mary's of the Lake Hospital Site

Dr. J. Low
Emeritus Professor, Department of Obstetrics and Gynaecology, Queen's University and Kingston General Hospital

Dr. H. Murray
Assistant Professor, Department of Emergency Medicine, Queen's University

Dr. W. Racine
Emeritus Professor, Department of Pharmacology & Toxicology, Queen's University

Dr. H. Richardson
Assistant Professor, Department of Community Health & Epidemiology Project Coordinator, NCIC CTG, Queen's University

Dr. H. Simelton
Assistant Professor, Department of Anesthesiology, Queen's University

Dr. A.N. Singh
WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology Chair and Head, Division of Psychopharmacology, Queen's University

Dr. S. Taylor
Director, Office of Bioethics, Queen's University and Kingston General Hospital; Associate Professor, Department of Medicine, Queen's University

Ms. K. Weisbaum
LL.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)

has examined the revised protocol and revised consent form for the project entitled "Experiences of Factors Affecting Activities and Participation in Persons with Disability" as proposed by Dr. Joy Wee of the Department of Physical Medicine and Rehabilitation at RCCHC, St. Mary's of the Lake and Dr. K. Osney and Dr. M. Paterson of the School of Rehabilitation Therapy at Queen's University and considers it to be ethically acceptable. This approval is valid for one year. If there are any amendments or changes to the protocol or the subjects in this study, it is the responsibility of the principal investigator to notify the Research Ethics Board. Any unexpected serious adverse event occurring locally must be reported within 7 working days of or earlier if requested by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

Chair, Research Ethics Board

Date: Dec 4, 2005

RMED-042-95
EX
April 20, 2006

Dr. Joy Wec
Department of Physical Medicine and Rehabilitation
Providence Continuing Care Centre
St. Mary’s of the Lake Site
340 Union Street
Kingston, ON

Re: “Experiences of Factors Affecting Activities and Participation in Persons with Disability” RMED-042-05

Dear Dr. Wec,

I am writing to acknowledge receipt of the following:

- Your letter dated March 14, 2006 which included copies of notices and advertisements and a sample letter of invitation for potential participants who are your patients
- Your letter dated April 11, 2006 which included a modified version of the Letter of Invitation to be used for potential participants who are not your patients

I have reviewed these materials and hereby give my approval. Receipt of these materials will be reported to the Research Ethics Board.

Yours sincerely,

[Signature]

Albert Clark, Ph.D.
Chair
Research Ethics Board

AFCkr

think Research

think Queen's

PREPARING LEADERS AND CITIZENS FOR A GLOBAL SOCIETY

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QUEEN’S UNIVERSITY HEALTH SCIENCES AND AFFILIATED TEACHING HOSPITALS
ANNUAL RENEWAL

Queen’s University, in accordance with the “Tri-Council Policy Statement, 1998” prepared by the Medical Research Council, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada requires that research projects involving human subjects be reviewed annually to determine their acceptability on ethical grounds.

A Research Ethics Board composed of:

Dr. A.F. Clark  Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen’s University (Chair)
Dr. S. Burke  Emeritus Professor, School of Nursing, Queen’s University
Rev. T. Deline  Community Member
Dr. M. Evans  Community Member
Mrs. C. Kenny  Community Member
Dr. J. Low  Professor, Department of Obstetrics and Gynaecology, Queen’s University and Kingston General Hospital
Dr. W. Raczk  Emeritus Professor, Department of Pharmacology & Toxicology, Queen’s University
Dr. H. Richardson  Assistant Professor, Department of Community Health & Epidemiology, Project Coordinator, NCIC CTG, Queen’s University
Dr. B. Simchison  Assistant Professor, Department of Anaesthesia, Queen’s University
Dr. A.N. Singh  WHO Professor in Psychosomatic Medicine and Psychopharmacology, Professor of Psychiatry and Pharmacology, Chair and Head, Division of Psychopharmacology, Queen’s University, Director & Chief of Psychiatry, Academic Unit, Queen Health Care, Belleville General Hospital
Dr. M. Sommerfeld  Physician and Assistant Professor, Department of Family Medicine, Queen’s University
Dr. E. Tsai  Assistant Professor, Department of Paediatrics and Office of Bioethics, Queen’s University
Ms. K. Weissbaum  LL.D. and Adjunct Instructor, Department of Family Medicine (Bioethics)

has reviewed the request for renewal of Research Ethics Board approval for the project “Experiences of Factors Affecting Activities and Participation in Persons with Disability” as proposed by Dr. Joy Woe of the Department of Physical Medicine and Rehabilitation at PCCC, St. Mary’s of the Lake Hospital and Dr. S. Olney and Dr. M. Paterson of the School of Rehabilitation Therapy at Queen’s University. The approval is renewed for one year, effective December 6, 2006. If there are any further amendments or changes to the protocol affecting the subjects in this study it is the responsibility of the principal investigator to notify the Research Ethics Board. Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other adverse events must be reported within 15 days after becoming aware of the information.”

Chair, Research Ethics Board  Date

Oct 13, 2006

208
January 25, 2006

Dr. Joy Wee
Physical Medicine & Rehabilitation
St. Mary’s of the Lake Hospital

Re: Experiences of Factors Affecting Activities and Participation in Persons’ with Disability

Dear Dr. Wee,

Thank you for your letter of January 10, 2006 addressing the recommendations of the PCCC Research Review Committee regarding the above named proposal.

I am satisfied that the issues have been addressed satisfactorily and am pleased, on behalf of the committee, to provide approval for your project to proceed.

Appended is the Authorization and Notification of Approved Research Activity form, which we require you to complete and return to this office. It is designed to provide needed information to our Patient Records and Registration Services, which will in turn help them to provide you with better service.

Yours sincerely,

John P. P. M. D.
Chair, PCCC Research Review Committee

JP/gl

c: Ms. L.J. Edmonds, Director, Queen’s Office of Research Studies
Ms. Madeline Halladay, Director Patient Records & Registration
Sister Sheila Langton, Chair PCCC Ethics Committee
10 January 2006

Dr. Joy Woo
Department of Physical Medicine & Rehabilitation
Queen's University

Dear Dr. Wee:

On behalf of CTAQ and the SEAMO Endowment Fund Committee, I am very pleased to inform you that your application was successful. We have recommended funding of your project in the amount of $10,000. You will be notified when an account is set up in your name with Queen's Financial Services.

The terms of reference for the CTAQ endowment fund exclude funding for conference travel. The committee strongly recommends collaboration with individual(s) with demonstrated expertise in qualitative research to strengthen the proposal.

Please also be advised that, according to the terms of reference of this fund, funds not used within two years of the award must be returned and we also require an annual progress report and financial statement. There is a potential for re-application. We are looking forward to an update in one year and wish you success with your project.

Congratulations!

J MacKenzie

Dr. Jennifer MacKenzie
Chair
SEAMO Endowment Committee
Appendix C

Date:

Dear

You have been identified as someone who might be interested in a study regarding persons with disabilities. The purpose of the study is to determine what factors are important in helping or hindering persons with disabilities in participating in activities, both in and outside of the home. Your involvement would be valuable and much appreciated.

Details of the study are attached. If you are interested in it, please contact me for a screening assessment.

Thank you for considering this study.

Sincerely,

Joy Wee, MD, FRCPC
Department of Physical Medicine & Rehabilitation,
Queen’s University
Tel: 613-544-2143
Appendix D

My M.Sc. project, “Experiences of Factors affecting Activities and Participation in Persons with Disability,” is now approved by all ethics committees, and is ready to get underway. The purpose of the study is to determine factors that affect activities and participation, and the reporting of such factors with standard outcome measures.

I’d be appreciative of your assistance in identifying any potential participants. Eligibility criteria are as follows:

1. Individuals with relatively stable neurological or musculoskeletal impairments who require mobility aids such as a wheelchair or walkers will be enrolled.

2. Participants must have lived in the community for at least 12 months with their generally static or very slowly progressive disability (no noticeable change in function for 1 year).

3. Participants must be able to participate in activities and participation to some degree.

4. Participants must be age 16 or older, and willing to be interviewed in depth at his/her home, or at St. Mary’s of the Lake Hospital site.

Potential participants will be screened prior to enrolment, for ability to participate in such an interview process.

Your assistance in identifying potential participants is greatly appreciated.
Appenlix E

Seeking Volunteers

Walker and Wheelchair Users, we need your help in a Research Study.

Have you been using a wheelchair or walker regularly for at least a year, and are medically stable?

Would you like to help health care providers communicate effectively about peoples’ functioning at home and in the community?

If you would like to share your experiences through an interview, and want to know more, please call Dr. Wee, rehabilitation physician: 613-544-2143.
## Mental Status Examination

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<td>Recall</td>
<td>(3)</td>
</tr>
<tr>
<td>Language</td>
<td></td>
</tr>
<tr>
<td>Naming</td>
<td>(2)</td>
</tr>
<tr>
<td>Repetition</td>
<td>(1)</td>
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<tr>
<td>Command</td>
<td>(3)</td>
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<tr>
<td>Read</td>
<td>(1)</td>
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<tr>
<td>Write</td>
<td>(1)</td>
</tr>
<tr>
<td>Copy</td>
<td>(1)</td>
</tr>
</tbody>
</table>

**Total Score** \(\text{____}/30\)

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*Adapted from Folstein, J Psych Res 1975*
Appendix G

Experiences of Factors affecting Activities and Participation in Persons with Disability – Letter of Information and Consent form

Primary Investigator: Dr. Joy Wee  St. Mary’s of the Lake Hospital,  Providence Continuing Care Centre  Kingston, Ontario, Canada  Telephone: 613-544-2143

You are invited to be part of a research study by Dr. Joy Wee. This study explores the factors that influence what you are able to do in daily life, in order to understand how these factors affect persons with disabilities. I will interview you, and this interviewed data will be collected. Through this study, I hope to find ways to improve the lives of persons with disabilities.

To be eligible, you need to have a permanent disability that has been relatively stable for the past year, that causes you to need a walker or wheelchair to get around. You must also have a good memory, and a test will be done to assess your memory and thinking.

If eligible for this study, you will be asked to provide information about how you have been in the past year. You will be asked to provide information about yourself, such as age, occupation, and supports, and answer questions about your abilities and community participation.

The time required would be at least one hour for the interview. If you have a caregiver living with you, they will also be asked to answer these questions independently, with your permission. You are not obliged to consent to interviews of caregivers. You will be asked to review a summary of the interview sometime in the future, to make sure the information is correct.

There are no known physical, psychological, economic, or social risks in this study. A potential benefit would be the identification of a factor or factors that could be changed to allow you to do more activities at home or in your community. The aim of this effort is to find better ways of reporting these factors along with outcome measures that are used by health professionals, for better understanding and communication overall.

Your participation is entirely voluntary, and you can stop at any time. Your current and future medical care will not be affected by your participation in, or withdrawal from, this
study. You are not obliged to answer any question that makes you uncomfortable. Your answers will be recorded in written form on questionnaires, and tape-recorded.

In order to maintain confidentiality, you will be assigned an ID number. At no time will any information be published which will identify you by name, except where required by law. The only people who will have direct access to information I collect are the study investigators and personnel, and Research Ethics Boards upon demand. Data will be kept in a locked filing cabinet in Dr. Wee’s office.

It is intended that the results of this study be published in a relevant rehabilitation publication. They may also be used to plan future studies that may help persons with disability in your area. If you would like to get a copy of the results of the study, please indicate so below.

There is no payment for participating in this study. However, should you choose to have the interview done at PCCC-SMOL, parking costs at the hospital and mileage to and from your home will be reimbursed at the rate accepted by Queen’s University. A copy of this letter of information and signed consent form will be provided to you.

If you have questions at any time, you may contact Dr. Wee. Alternatively, you could contact Dr. Sandra Olney, Department Head, School of Rehabilitation Sciences (613-533-6102), at Queen’s University, or Dr. Karen Smith, Head, Department of Physical Medicine & Rehabilitation (613-544-1894) with any questions or concerns. You may also contact Dr. Albert Clark, Chair of the Queen’s University research ethics board (613-533-6081) with any questions, concerns, or complaints about the research procedures.
Consent Form

Experiences of Factors affecting Activities and Participation in Persons with Disability

Participant statement and signature section
I, ______________________, have read the letter of information provided for this study, and have had questions answered to my satisfaction. I understand that I will be participating in the above-named study, and that its purpose is to understand factors affecting activities and community participation of persons with disability. I understand that my participation in this study is entirely voluntary, and that I may withdraw at any time.

I have been assured that in order to maintain confidentiality, my name will not be attached to any of the forms used in the study, other than this one. I understand that data collected will be recorded on tape and in writing, and stored in a secure location.

I am aware that I may contact the researcher(s), and/or the research ethics board with any questions, complaints, or concerns.

I give Dr. Wee permission to interview my caregiver __________________ for this study.

I would like a copy of the results of this study: Yes/No

Name: ______________________________ ID: ______________
Signature: ___________________________ Date: ______________
Witness: ____________________________ Date: ______________

Statement of Investigator:
I, or one of my colleagues, have carefully explained to the subject the nature of the above research study. I certify that, to the best of my knowledge, the subject understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

Signature (Principal Investigator): ______________ Date: ______________
Appendix H

Questions to be used in conjunction with BI and P Scale:

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)
### Factors affecting Barthel Index

<table>
<thead>
<tr>
<th>Score</th>
<th>Factors</th>
<th>Adjusted Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding</td>
<td>with help-5</td>
<td></td>
</tr>
<tr>
<td>I if within reach-10</td>
<td></td>
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<tr>
<td>Bed to chair</td>
<td>I bed, maj tf –5</td>
<td></td>
</tr>
<tr>
<td>Min/sup – 10, I, safe-15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal toilet</td>
<td>I (shaving, make-up)-5</td>
<td></td>
</tr>
<tr>
<td>On/off toilet</td>
<td>help (clothes, paper)-5</td>
<td></td>
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<tr>
<td>I, complete</td>
<td>(cleans bed-pan) – 10</td>
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</tr>
<tr>
<td>Bathing</td>
<td>without another present-5</td>
<td></td>
</tr>
<tr>
<td>Walking</td>
<td>W/C 50y – 5</td>
<td></td>
</tr>
<tr>
<td>Help/sup 50y – 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I aids, not roll-walker-15</td>
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<td></td>
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<tr>
<td>Stairs</td>
<td>help/sup – 5</td>
<td></td>
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<tr>
<td>Safe, I – 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>help &lt;1/2 – 5</td>
<td></td>
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<tr>
<td>I – 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowels</td>
<td>occ incont/help-5</td>
<td></td>
</tr>
<tr>
<td>I, cont – 10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bladder</td>
<td>occ incont/help-5</td>
<td></td>
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<tr>
<td>Cont – 10</td>
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</table>

**Total:** ____  ____

Adapted from the Barthel Index, Maryland State Medical Journal, Feb 1965: 61-65.
Factors affecting Participation Scale

ID __________
Diagnosis___________
Date ____________

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<th>Adjusted Score</th>
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</thead>
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<td>2. work/peers</td>
<td>____</td>
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<td>3. economic</td>
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<td>4. travel</td>
<td>____</td>
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<td>5. help others</td>
<td>____</td>
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</tr>
<tr>
<td>6. recreation</td>
<td>____</td>
<td></td>
<td>____</td>
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<tr>
<td>7. social</td>
<td>____</td>
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<td>8. visit others</td>
<td>____</td>
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<td>9. new people</td>
<td>____</td>
<td></td>
<td>____</td>
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<tr>
<td>10. respect</td>
<td>____</td>
<td></td>
<td>____</td>
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<tr>
<td>11. access</td>
<td>____</td>
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<td>12. public access</td>
<td>____</td>
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<td>13. health</td>
<td>____</td>
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<td>14. housework</td>
<td>____</td>
<td></td>
<td>____</td>
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<tr>
<td>15. opinion</td>
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<td></td>
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<td>16. meals</td>
<td>____</td>
<td></td>
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<tr>
<td>17. festivals, rituals</td>
<td>____</td>
<td>____</td>
<td></td>
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<tr>
<td>18. new learning</td>
<td>____</td>
<td></td>
<td>____</td>
</tr>
</tbody>
</table>

To be used in conjunction with Participation Scale 25 Feb 2003 version
Demographic Information

ID _______________________   DOB________________
Address      Postal Code__________

Other family members’ ages/gender/relation:

Community: Agricultural/Cottage/Residential/Industrial/Remote/Urban/Suburban
Distance to neighbours _________________ meters/km
Distance to nearest grocery store______________
Distance to nearest gasoline pump______________
Distance to nearest hardware store _____________
Distance to nearest library_______________
Distance to nearest elementary school ________ secondary school __________
Distance to nearest hospital _________________
Distance to nearest clinic __________________
Distance to family physician _________________ (no physician)

Available services:

Municipal water/sewer/garbage pickup/recycling/street clearing/emergency services/public
transportation/accessible public transportation/accessible transportation

Highest education achieved: elementary;secondary school; college; university first degree;
doctrate; post-doctorate

Employment/Occupation __________________________P/T;F/T;retired
Income: Below $35 000/yr; $35 000-70 000/yr; over $70 000/yr
Appendix I

BARTHEL INDEX

With Help Independent

1. Feeding (if food needs to be cut up = help) 5 10
2. Moving from wheelchair to bed and return (includes sitting up in bed) 5-10 15
3. Personal toilet (wash face, comb hair, shave, clean teeth) 0 5
4. Getting on and off toilet (handling clothes, wipe, flush) 5 10
5. Bathing self 0 5
6. Walking on level surface (or if unable to walk, propel wheelchair) 0* 5*
   *score only if unable to walk
7. Ascend and descend stairs 5 10
8. Dressing (includes tying shoes, fastening fasteners) 5 10
9. Controlling bowels 5 10
10. Controlling bladder 5 10

A patient scoring 100 BI is continent, feeds himself, dresses himself, gets up out of bed and chairs, bathes himself, walks at least a block, and can ascend and descend stairs. This does not mean that he is able to live alone: he may not be able to cook, keep house, and meet the public, but he is able to get along without attendant care.

DEFINITION AND DISCUSSION OF SCORING

1. Feeding
   10 = Independent. The patient can feed himself a meal from a tray or table when someone puts the food within his reach. He must put on an assistive device if this is needed, cut up the food, use salt and pepper, spread butter, etc. He must accomplish this in a reasonable time.
   5 = Some help is necessary (with cutting up food, etc., as listed above).

2. Moving from wheelchair to bed and return
   15 = Independent in all phases of this activity. Patient can safely approach the bed in his wheelchair, lock brakes, lift footrests, move safely to bed, lie down, come to a sitting position on the side of the bed, change the position of the wheelchair, if necessary, to transfer back into it safely, and return to the wheelchair.
   10 = Either some minimal help is needed in some step of this activity or the patient needs to be reminded or supervised for safety of one or more parts of this activity.
   5 = Patient can come to a sitting position without the help of a second person but needs to be lifted out of bed, or if he transfers with a great deal of help.


3. Doing personal toilet
   5 = Patient can wash hands and face, comb hair, clean teeth, and shave. He may use any kind of razor but must put in blade or plug in razor without help as well as get it from drawer or cabinet. Female patients must put on own makeup, if used, but need not braid or style hair.
4. Getting on and off toilet
10 = Patient is able to get on and off toilet, fasten and unfasten clothes, prevent soiling of clothes, and use toilet paper without help. He may use a wall bar or other stable object for support if needed. If it is necessary to use a bed pan instead of a toilet, he must be able to place it on a chair, empty it, and clean it. Patient needs help because of imbalance or in handling clothes or in using toilet paper.

5. Bathing self
5 = Patient may use a bath tub, a shower, or take a complete sponge bath. He must be able to do all the steps involved in whichever method is employed without another person being present.

6. Walking on a level surface
15 = Patient can walk at least 50 yards without help or supervision. He may wear braces or prostheses and use crutches, canes, or a walkerette but not a rolling walker. He must be able to lock and unlock braces if used, assume the standing position and sit down, get the necessary mechanical aides into position for use, and dispose of them when he sits. (Putting on and taking off braces is scored under dressing.)
10 = Patient needs help or supervision in any of the above but can walk at least 50 yards with a little help.

6a. Propelling a wheelchair
5 = If a patient cannot ambulate but can propel a wheelchair independently. He must be able to go around corners, turn around, maneuver the chair to a table, bed, toilet, etc. He must be able to push a chair at least 50 yards. Do not score this item if the patient gets score for walking.

7. Ascending and descending stairs
10 = Patient is able to go up and down a flight of stairs safely without help or supervision. He may and should use handrails, canes, or crutches when needed. He must be able to carry canes or crutches as he ascends or descends stairs.
5 = Patient needs help with or supervision of any one of the above items.

8. Dressing and undressing
10 = Patient is able to put on and remove and fasten all clothing, and tie shoe laces (unless it is necessary to use adaptations for this). The activity includes putting on and removing and fastening corset or braces when these are prescribed. Such special clothing as suspenders, loafer shoes, dresses that open down the front may be used when necessary.
5 = Patient needs help in putting on and removing or fastening any clothing. He must do at least half the work himself. He must accomplish this in a reasonable time. Women need not be scored on use of a brassiere or girdle unless these are prescribed garments.

9. Continence of bowels
10 = Patient is able to control his bowels and have no accidents. He can use a suppository or take an enema when necessary (as for spinal cord injury patients who have had bowel training).
5 = Patient needs help in using a suppository or taking an enema or has occasional accidents.

10. Controlling bladder
10 = Patient is able to control his bladder day and night. Spinal cord injury patients who wear an external device and leg bag must put them on independently, clean and empty bag, and stay dry day and night.
5 = Patient has occasional accidents or can not wait for the bed pan or get to the toilet in time or needs help with an external device.
A score of 0 is given in all of the above activities when the patient cannot meet the criteria as defined above.
The advantage of the BI is its simplicity. It is useful in evaluating a patient's state of independence before treatment, his progress as he undergoes treatment, and his status when he reaches maximum benefit. It can easily be understood by all who work with a patient and can accurately and quickly be scored by anyone who adheres to the definitions of items listed above. The total score is not as significant or meaningful as the breakdown into individual items, since these indicate where the deficiencies are.
Any applicant to a chronic hospital who scores 100 BI should be evaluated carefully before admission to see whether such hospitalization is indicated. Discharged patients with 100 BI should not require further physical therapy but may benefit from a home visit to see whether any environmental adjustments are indicated. Encouragement by family and others may be necessary for a patient to maintain his degree of independence.
## Participation Scale

**Compared to your peers...**

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
<th>Yes</th>
<th>Sometimes</th>
<th>No</th>
<th>Intermittent (at your own initiative)</th>
<th>No problem</th>
<th>Small</th>
<th>Medium</th>
<th>Large</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do you have equal opportunity as your peers to find work?</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<td>2</td>
<td>Do you work as hard as your peers do? (same hours, type of work etc)</td>
<td>0</td>
<td>0</td>
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<td>1 2 3 5</td>
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<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<tr>
<td>3</td>
<td>Do you contribute to the household economically in a similar way to your peers?</td>
<td>0</td>
<td>0</td>
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<td></td>
<td>1 2 3 5</td>
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<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<td>4</td>
<td>Do you make visits outside your village / neighbourhood as much as your peers do? (except for treatment) e.g. bazaars, markets</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
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<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<tr>
<td>5</td>
<td>Do you help other people (e.g. neighbours, friends or relatives)?</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
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<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<td>6</td>
<td>Do you take as much part in casual recreational/social activities as your peers? (e.g. sports, chat, meetings)</td>
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<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
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<tr>
<td>7</td>
<td>Are you as socially active as your peers are? (e.g. in religious/community affairs)</td>
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<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
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<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<tr>
<td>8</td>
<td>Do you visit other people in the community as often as other people do?</td>
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<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
<td></td>
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<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<tr>
<td>9</td>
<td>Are you comfortable meeting new people?</td>
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<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
<td></td>
<td></td>
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<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<tr>
<td>10</td>
<td>Do you have the same respect in the community as your peers?</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
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<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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<tr>
<td>11</td>
<td>Do you move around inside and outside the house and around the village / neighbourhood just as other people do?</td>
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<td>0</td>
<td></td>
<td></td>
<td>1 2 3 5</td>
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<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
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### Participation Scale

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<th>2</th>
<th>3</th>
<th>5</th>
<th>Score</th>
</tr>
</thead>
<tbody>
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<td>In your village/neighborhood, do you visit all the public places/common places? (including schools, shops, offices, market and tea/coffee shops)</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Do you have opportunity to look after yourself (appearance, nutrition, health, etc.) as well as your peers?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>In your home, do you do household work?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>In family discussions, does your opinion count?</td>
<td>0</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>In your home, are the eating utensils you use kept with those used by the rest of the household?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Do you take part in major festivals and rituals as your peers do? (e.g. weddings, funerals, religious festivals)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Do you feel confident to try and learn new things?</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(if sometimes, no or irrelevant) How big a problem is it to you?</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

**Comment:**

**Name:** ____________________________

**Age:** _______  **Gender:** _______

**Reason for the assessment:** ____________________________

**Interviewer:** ____________________________  **Date of interview:** __ / __ / ____

**Grades of participation restriction**

<table>
<thead>
<tr>
<th>Degree of restriction</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>No significant restriction</td>
<td>0 - 12</td>
</tr>
<tr>
<td>Mild restriction</td>
<td>13 - 22</td>
</tr>
<tr>
<td>Moderate restriction</td>
<td>23 - 32</td>
</tr>
<tr>
<td>Severe restriction</td>
<td>33 - 52</td>
</tr>
<tr>
<td>Extreme restriction</td>
<td>53 - 80</td>
</tr>
</tbody>
</table>

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