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**The Delivery of Assistive Technology Viewed From the Consumer Perspective:
Independent Living Considerations**

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**A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfilment of Requirements for the Degree of**

Master of Science

**Department of Community Health Sciences
Faculty of Medicine
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CONSUMER PERSPECTIVE: INDEPENDENT LIVING CONSIDERATIONS**

by

LAURIE ANNE RINGAERT

A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba
in partial fulfillment of the requirements of the degree of

MASTER OF SCIENCE

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**We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time**

T. S. Eliot

TABLE OF CONTENTS

	Page
Acknowledgments	2
Abstract	6
List of Tables	7
List of Figures	8
List of Appendices	9
Chapter 1: Introduction	
Significance of the Research	10
Definitions and Terms Used	11
Goal and Objectives	13
Chapter 2: Review of Related Literature	16
Assistive Technology	16
The Independent Living Movement	18
Assistive Technology and Government Policy	20
Professionalization of Assistive Technology	25
Chapter 3: Initial Conceptual Framework	27
The Individual and Environmental Determinants of Handicap Situations and Social Participation Model	28
Chapter 4: Research Design: Methodology, Methods & Implementation	35
Time Lines	36
Sample Selection	36
Access to Respondents	40
Phases in the Methodology	42
Managing and Recording Data	46
Data Analysis Strategies	47
Trustworthiness of the Study	49
Management of Researcher Role	49
Ethical Considerations	50
Chapter 5 - Results: The Core Category, The Conditions, The Context	55
The Core Category	55
Causal Conditions	58
The Context	63

Chapter 6 - Results: Intervening Conditions	82
Information Sources	83
Inequality of Distribution: Cost and Eligibility for Assistive Technology	92
The Impact of Bureaucracy on Equipment Acquisition Choice as a Barrier or Facilitator to Accessing Assistive Technology	100
Professionals as Barriers or Facilitators to Accessing Assistive Technology	115
Relationships with Assistive Technology Vendors	125
The Built Environment as a Determinant of Acquiring Assistive Technology	138
Relationship of Access to Assistive Technology and the Individual Environmental Determinants of Handicap Situations and Social Participation Model	143
	148
Chapter 7 - Results: Strategies for Acquiring Assistive Technologies Needed For Independence	157
Play the Game	158
Peer Support	160
Resource Network	167
Speaking Up	170
Invention	173
Chapter 8 - Results: Consequences	185
Chapter 9 - Recommendations and Conclusions	
Major Findings	190
Findings Beyond Original Objectives	198
Modified Conceptual Model	202
Study Limitations and Methodological Issues	207
Implications of Findings	210
Direction for Future Research	210
Policy Implications	213
Practice Implications for Professionals, Vendors, and Disability-Related Organizations	214
Conclusion	217
References	218
Appendices	223

Abstract

THE DELIVERY OF ASSISTIVE TECHNOLOGY VIEWED FROM THE CONSUMER PERSPECTIVE: INDEPENDENT LIVING CONSIDERATIONS

Objective The goal of this study is to describe the experiences of adult consumers with disabilities who receive assistive technology service delivery in Manitoba. The study examines the impact of the delivery of assistive technology on the consumer's ability to live independently in the community. Experiences of persons with disabilities, both with and without involvement in the Independent Living movement, are explored. Their perceptions of the delivery of the assistive technology including professional, political, and vendor relationships are described.

Method Seventeen adults with a range of disabilities, who were either highly or minimally involved with the Independent Living Movement, participated in tape-recorded semi-structured interviews from November 1994 to February 1995. The respondents were asked what it was like to acquire equipment and about their relationships with professionals and vendors. Data were coded to facilitate analysis using thematic categories including barriers and facilitators influencing access to assistive technology and strategies for overcoming obstacles. A modified critical ethnographic methodology was used.

Results Barriers to getting equipment included its cost, the eligibility requirements, lack of information, lack of choice, complicated bureaucracies, attitudes of professionals and vendors, and the lack of an accessible environment. To overcome these barriers individuals developed various strategies including: "playing the game", the invention of new assistive technology, peer support, the development of resource networks, and speaking up for what they needed. Participants offered recommendations for improvement in the delivery of assistive technology which include providing consumers with funds to purchase their own assistive technology and maintaining a product display centre. Participants recommended that a government-funded program be maintained, but that a new program incorporate Independent Living principles.

Conclusion The delivery of assistive technology in Manitoba was perceived by participants to offer minimal opportunities for application of basic elements of Independent Living Principles. Both consumers and the researcher recommended changes to improve service delivery and make it more compatible with the Independent Living model of service delivery.

LIST OF TABLES

		Page
Table 1	Persons with Moderate and Severe Disabilities Aged 15 to 64 Reporting Using or Needing Mobility Aids	23
Table 2	Definitions of Terms in Strauss and Corbin Paradigm Model	52
Table 3	Critique of Each Assistive Technology Acquisition Method	80
Table 4	Intervening Conditions: Barriers and Facilitators to Acquiring Assistive Technology	155
Table 5	Relationships Between Strategies and Barriers	184
Table 6	Relationship Between Independent Living Principles and Government Sponsored Assistive Technology System	195

LIST OF FIGURES

		Page
Figure 1	Initial Conceptual Framework	31
Figure 2	Determinants of Handicap	32
Figure 3	The Individual and Environment Determinants of Handicap Situations and Social Participation Model (Whiteneck & Fougeyrollas, 1996)	33
Figure 4	Examples of Environmental Factors By Environmental Characteristics and Impairment Groups	34
Figure 5	Flow Chart of Sampling Process	38
Figure 6	Phases in the Methodology	43
Figure 7	The Paradigm Model Related to the Study Findings	53
Figure 8	How Equipment is Obtained: Acquisition Route 1	72
Figure 9	How Equipment is Obtained: Acquisition Route 2	75
Figure 10	How Equipment is Obtained: Acquisition Route 3	78
Figure 11	Initial Conceptual Model	204
Figure 12	Modified Conceptual Model: Present Situation	205
Figure 13	Modified Conceptual Model: with Proposed Facilitators	206

LIST OF APPENDICES

	Page
Appendix A-1: Letters of Permission From Fougeyrollas for Use of Model	224
Appendix A: Descriptions of Ten Ten Sinclair and Fokus Housing	225
Appendix B: Letters of Entry	226
Appendix C: Information About the Study (Paraphrase)	237
Appendix D: Screening Interview	240
Appendix E: Consent to Participate in Study	241
Appendix F: Record of Interview	242
Appendix G: Interview Procedures	243
Appendix H: Invitation to Participate in Forum	250
Appendix I: Data Analysis: Summary Form Sample	251
Appendix J: Time Line	252
Appendix K: Letters Requesting Information	253

CHAPTER 1 - INTRODUCTION

The Independent Living Movement is a major social movement, initiated by consumers with disabilities, which seeks opportunities and rights equal to those enjoyed by non-disabled persons. It is seen as a major force in the emancipation of persons with disabilities (Enns, 1986). An important component of living independently with a disability is assistive technology - equipment made for persons with disabilities which enables increased independence in everyday living.

Assistive technology has traditionally been provided at the recommendation of a professional, not at the request of the consumer. Recent societal changes which challenge the current assumptions in the delivery of this equipment include:

- the increased influence of the Independent Living Movement reflected in the demand of consumers for rights and control
- policies and laws that mandate rights for consumers with disabilities.

These changes have occurred during a period of other societal changes such as decreasing health-care resources and a proliferation of assistive-technology vendors. Current changes in societal attitudes brought about by these and other factors force a re-examination of the delivery of these services within the paradigm of the Independent Living Movement. Very little information exists that measures the impact of assistive technology on persons with disabilities. The impact of the current delivery of assistive technology has not been thoroughly examined in the light of these societal changes.

Significance of the Research

Little systematic documentation of the consumer's perspective on the delivery of assistive technology has been found. While some research has been done in the United States, the Canadian system has virtually remained unexamined. It is essential that we begin to study our own system within the context of Canadian culture including our political, legal and health care systems.

This research is of potential interest to a number of groups. Disability consumer groups need to know if services are delivered according to their expectations. Governments, rehabilitation professionals, and vendors are interested in ways of delivering the most cost effective and efficient services. It is hoped that this research will become a step toward enhancing our present delivery of assistive technology.

Definitions and Terms Used

For the purposes of this study **assistive technology** is defined by the widely used definition provided in (Public law) 100-407, the Technical Assistance to the States Act in the United States. The definition of an **assistive technology** device is

Any item, piece of equipment or product system whether acquired commercially off the shelf, modified, or customized that is used to increase or improve functional capabilities of individuals with disabilities. (Cook & Hussey, 1995: p.5)

This definition encompasses both complex high-technology devices such as computerized wheelchairs and environmental control systems and simpler low technology devices like walkers and bath seats.

The United States (Public Law 100-407) defines **assistive technology service** as "any service that directly assists an individual with a disability in the selection, acquisition or use of an assistive technology device" (Cook & Hussey, 1995: p. 6).

The law further clarifies the definition with the inclusion of evaluation needs and skills for assistive technology; the acquisition of assistive technology; the selection, design, repair, and fabrication of assistive technology systems; the coordination of services with other therapies; and the training of individuals with disabilities and those working with them to use the technologies effectively. This definition demonstrates the broad spectrum of services inherent in the delivery of assistive technologies. (Cook & Hussey, 1995)

For this study, **Mobility and Agility Disabilities** are defined by the definitions provided in the Health Activity Limitation Survey (HALS).

"Mobility Disability is a limitation in walking, moving from room to room, carrying an object 10 metres, or standing for long periods." (Health Activity Limitation Survey, Statistics Canada, 1990)

"Agility Disability is a limitation in bending, dressing, getting in or out of bed, cutting toenails, grasping objects reaching or cutting food. (Health Activity Limitation Survey, Statistics Canada, 1990)

The terms "assistive technology", "assistive devices", "assistive equipment" and "equipment" are all used interchangeably in this document because the term "assistive technology" is a relatively new technical term that is not yet fully integrated into the language of consumers with disabilities or with professionals.

As well, every attempt has been made to use **“person first language”** where the term **“person/consumer with a disability”** is preferred over **“disabled consumer”** or **“disabled person”**. This emphasizes the point that although the person happens to have a disability, he or she is a person first and should be considered as such.

The term **“consumer”** is often interchanged with **“respondent”** or **“person with a disability”** to reflect the current terminology of the Independent Living Movement. The term **“client”** is used when in reference to relationships with professionals.

Another term used in this study is **“bureaucracy”**. This term was described and defined by the respondents themselves to mean inflexibility and multiple layers of officials/professionals and procedures to get through in order to obtain assistive technology.

The term **“medical model or traditional rehabilitation model”** in this study is that defined by DeJong (1979) as one where the role of the person with a disability is a patient/client, the professional controls access to services, the definition of the problem is with the **“patient’s”** mental or physical impairments and the professional has ultimate control.

Goal and Objectives

The overall goal of this study is to describe the experiences of adult consumers with disabilities with assistive technology service delivery in Manitoba. The study examines the impact of the delivery of assistive technology on the consumer’s ability to live independently in the community. Experiences of persons with disabilities, both with and with no involvement in the Independent Living Movement, are explored. Their

perceptions of the delivery of the assistive technology including professional, political, and vendor relationships are described.

The Specific Objectives of the Study Are:

1. To describe the experiences of urban dwelling adults with disabilities with the delivery of assistive technology service in Manitoba.
2. To identify the barriers and facilitators in the present delivery of assistive technology that inhibit/promote independent living.
3. To describe the extent to which the delivery of assistive technology in Manitoba facilitates achievement of Independent Living principles.
4. To describe the social and political contexts within which the delivery of assistive technology to adults in Manitoba occurs, including organizational and historical perspectives.

In order to integrate the knowledge from previous studies in the area of assistive technology service delivery and to address the research goals and objectives outlined in this introduction, this thesis includes the following chapters and associated content:

- **Chapter 2: Literature Review** - summarizes and integrates previous literature exploring the nature of the delivery of assistive technology and consumer perspectives of this service delivery
- **Chapter 3: Initial Conceptual Framework**- presents the framework developed as a result of the literature review in order to guide the study design, implementation and analysis. It also describes an existing conceptual model which guided the analysis.
- **Chapter 4: Research Design, Methodology, Methods and Implementation** - describes the overall design of the study including sampling, instrumentation and

analysis, ethical considerations, and the implementation, chronology of the fieldwork and introduction to the Paradigm Model used in analysis

- **Chapter 5: Core Category, Conditions and Context-** describes the first three categories of the Paradigm model. Includes a summary of participant characteristics including the types of assistive technology they used, a discussion of the core category of getting equipment needed for independence. Also includes a description of the context: the delivery of assistive technology in Manitoba
- **Chapter 6: Intervening Conditions-** uses the participants' narratives to describe barriers and facilitators to getting equipment needed for independence
- **Chapter 7: Strategies for Getting Equipment-** uses the participant narratives to describe strategies used to overcome barriers to getting equipment
- **Chapter 8: Consequences** - uses the participant narratives to describe the consequences of getting or not getting equipment.
- **Chapter 9: Conclusions-** summarizes the primary findings of this study, the modified conceptual model, the study limitations and the implications for future research, policy and practise

CHAPTER 2: REVIEW OF RELATED LITERATURE

This literature review will focus on the following areas: assistive technology; the Independent Living movement; assistive technology and government policy; and professionalization of assistive technology.

Assistive Technology

Assistive technology is seen as necessary to living independently with a disability. Assistive technology can make the difference between a person with a disability becoming self-supporting or remaining dependent on government support (Phillips, 1990). The primary goal of assistive technology is to reduce the impact of physical impairment by providing a bridge between an individual's functional limitations and the demands of the physical environment (Friedmann and Capulong, 1984). In a comprehensive study of the financing of assistive technology, conducted by the National Council on Disability (1993) in the United States, individuals and families reported that as a result of assistive technology

- about 62% of working age persons were able to reduce dependence on their family members and 58% were able to reduce dependence on paid assistance
- about 92% of employed persons reported that assistive technology helped them to work faster or better, 83% indicated that they earned more money and 67% indicated that assistive technology helped them obtain employment.

Most studies of assistive technology tend to look at case histories of users'

experience with individual items, mechanical aspects of the item, utilization and reasons for abandonment of items. (Brooks, 1991; Rogers & Holm, 1992; Phillips & Zhou, 1993)

There have been very few studies which examine the social, political outcomes or in-depth consumer perspectives of assistive technology. Brooks (1991) surveyed 595 American scientists and engineers with disabilities to investigate how assistive technologies utilized in social settings were perceived by persons with disabilities who also maintained these occupational positions. Variations in device use within public and private settings and differences in attitudes associated with differences in demographic and disability characteristics were found. Users themselves suggested that further research be conducted to examine the systems that develop and distribute assistive devices. This recommendation was based on two concerns: that the systems which provide assistive devices were neither clearly defined nor readily available to the user. The informants commented that the process of obtaining assistive devices was frustrating.

In a qualitative study, Miles-Tapping and MacDonald (1994) explored the lifestyle implications of power mobility. The technology users in the study described their sense of empowerment which resulted from access to their electric mobility aids. As well, they stated that this technology enabled them to be more productive, enjoy more leisure, and accomplish more selfcare. In another qualitative study, Scherer (1993) followed a small number of individuals with disabilities and examined how technology impacted on their lives and to “get inside” the disability experience. Both studies illustrated the importance of assistive technology to consumers’ lives. However, there is little information in either

study about the experience of assistive technology acquisition or dealings with professionals.

The Independent Living Movement

The Independent Living Movement began in the 1970s as the result of grassroots efforts to influence disability policies. The Movement has been described as a product of a number of contemporary social movements including the rise of consumerism, civil rights, and the self-help focus. (Zukas, 1975, DeJong, 1979). Within the Independent Living paradigm, the person with a disability is defined as a consumer rather than as a patient or client. This paradigm provides an alternative to the medical and rehabilitation models which focus on the limitations of the individual and on his/her inadequate performance of daily living tasks. (DeJong 1979, Crewe & Zola 1984, Enns, 1986). Within the Independent Living paradigm, problems are defined in terms of barriers in the environment including economic, architectural, or support systems rather than in terms of the consumer's physical and/or mental disabilities (DeJong, 1979). As well, the paradigm emphasizes that pathology can be found in unprotected rights and in over-dependency on relatives and professionals (Dunn, 1994).

Harlan Hahn, a well known American disability rights advocate, has described the "minority-group" model (1988). This model emphasizes that environmental barriers have more impact than biological or psychological forces in shaping major life experiences of persons with disabilities. He argues that having to live with the shared constraints of inaccessible physical, social, and communicative environments and being denied equal

access to education, employment, transportation, and housing while contending with negative stereotypes and minimal political power has constructed a distinct minority-group experience which includes the segregation, discrimination, and exploitation of people with disabilities (Hahn, 1988). Brooks (1991) also comments that the lack of study about users' responses to disability technology demonstrates the disadvantaged (minority group) position of persons with disabilities. Hahn's minority perspective is congruent with the principles of the Independent Living movement which place emphasis on the environment rather than on the individual.

The Independent Living movement defines independent living as

“The process of translating into reality the theory that, given appropriate supportive services, accessible environments, and pertinent information and skills, severely disabled individuals may actively participate in all aspects of society” (Crewe & Zola, 1983 p. 25)

“Independence” according to the Independent Living (IL) movement has been described by the following principles:

- to take part in all aspects of society as non-disabled people do
(Derksen, 1983)
- to live outside of an institution (Kibele, 1989)
- to have control over one's life (Rock, 1988; Frieden & Cole, 1985)
- to include decision making (Rock 1988, Kibele 1989)
- to include freedom of choice (Lord & Osborne-Way, 1987)
- to be able to engage in risk taking (DeJong 1979, Rock 1988)

The latter four principles are particularly important to the process of engaging in

assistive technology.

The Movement recognizes "independence" through dependence upon social and technological support. Such an interpretation presents a vision of "independence" as mutual dependence, also referred to as interdependence. (Townsend & Ryan, 1991). Rogers and Holm (1992) also pointed out that devices that do not provide independence for the individual may provide assistance for caregivers. This aspect is important in the Independent Living paradigm which recognizes "independence" with caregiver support.

The primary meaning of independence to the Independent Living Movement is the ability to have control over one's life in the community (Crewe and Zola, 1984). In many situations, control is facilitated through the consumer's use of assistive technologies and attendant care. In contrast, the traditional rehabilitation definition of independence focuses on individual physical performance (DeJong, 1979, Jongbloed and Crichton, 1990, Law, 1991) in which assistive technologies are used to increase physical functioning. However, Zola (1982) pointed out that consumers prefer devices that facilitate independence associated with social and psychological freedoms, not just physical functioning.

Assistive Technology And Government Policy

Governments play a central role in the allocation of assistive technology. The United Nations declared 1981 the International Year of Disabled Persons and the beginning of a concerted effort to promote independent living. Later the period from 1983 to 1992 was declared the Decade of Disabled Persons to highlight the importance of responding to the needs of individuals with disabilities around the world. Government organizations have begun slowly to incorporate independent living concepts into some

policies and programs as a result of consumer advocacy efforts. However, according to Dunn (1994) most individuals who are disabled in Canada still confront a multitude of barriers which include economic, architectural, transportation, and as Dunn commented, "paternalistic" barriers. These barriers include the inability or unwillingness of professionals to accept people with disabilities as experts about their own needs.

Many persons with disabilities have low incomes. In 1986 approximately 57% of individuals with disabilities had incomes below \$10,000 (Ross & Shillington, 1990). According to Dunn (1994) roughly 15% were unemployed, more than 80% did not have any post-secondary education, and only 42% of individuals that require special transportation received it. Dunn (1990) used the 1986 Health Activity Limitation Survey (HALS) data base to study barriers confronting seniors with disabilities. He found that 8% of the disabled seniors in non-institutional households who required mobility aids did not have them mainly due to the primary barrier of cost. Although Dunn's study focuses predominantly on the experiences of seniors, it may also illustrate a difficulty that younger adult persons with disabilities face. Having low incomes and complex health conditions, persons with disabilities are often dependent on public programs for decisions about technology.

In Canada, assistive technologies come under the umbrella of personal supports. "Personal supports" also includes attendant services, home health care, homemaker services, and respite care. However, there are no common agreed-upon definitions of personal supports (Dunn, 1994). Dunn (1994) conducted a survey of several government departments in Canada and found that policies related to personal supports are often

complex and confusing. There are multiple levels of jurisdiction, and individuals with different disabilities and ages fall under different government departments. Torjman (1993) pointed out a number of problems with the overall system of personal supports in Canada including access (disparities in availability, complexities, high costs), complicated eligibility rules, and unresponsiveness to consumer needs. As well, the author discusses that these services reinforce dependency relations, paternalism, and the medical model. Dunn (1994) concluded that although there has been a movement toward independent living policies, this has been eroded by profound reductions in public expenditures in the 1990's. However, neither Dunn (1994) nor Torjman (1993) examined assistive technology services independently from other services in either of these studies.

In most instances in North America, individuals receive support for basic equipment such as toileting equipment but not for higher level activities such as communication boards, environmental control systems, or car modifications. Seelman (1993) commented that by supporting lower human functions but not functions that support independent living, the government is inadvertently supporting the health care industry and professional control of the individual rather than supporting the individual in community integration.

According to Brooks (1991), existing distribution systems exert strong social control over allocation of assistive devices. Allocation is often based on the particular department's definition of disability as well as public attitudes which often reflect the historic prejudice experienced by individuals with disabilities (Seelman, 1993). In the United States, there is evidence of denials by third party payers of requests for approval of

funding of technology. (Donovan, Carter, Wilkerson, 1987).

There is evidence that individuals do not have the technology that they require. Some 1991 Health Activity Limitation Survey results for individuals with severe and moderate mobility disabilities are summarized in Table 1.

Table (1)
Persons With Moderate And Severe
Disabilities Aged 15 To 64 Reporting Using Or Needing Mobility Aids

	Using	Needing	Total	% Needing
Canada	213,680	73,445	287,125	25.6%
Manitoba	6230	2480	8710	28.5%
Winnipeg	3424	1300	4724	27.5%

(Adapted from Statistics Canada, 1993)

Table 1 demonstrates that considering those reporting a mobility disability in the 15 to 64 age category, nationally 25.6% did not have the mobility device they needed. This percentage was higher in Manitoba (28.5%) and in Winnipeg (27.5%) than the national level of unmet needs. Much of the data regarding agility disabilities was not recorded in this report from Statistics Canada, therefore a similar table could not be made. At this time there is little documentation of the numbers of other assistive technologies in use or needed by consumers in Canada.

Manitoba is recognized for providing the most extensive support services for people with disabilities in Canada (Dunn, 1994). One of the most innovative programs is individualized funding in which funding is given directly to the consumer to hire, fire and direct his/her own support worker. However, there has not been a similar program for assistive technology.

Brooks (1991) commented that distribution problems will persist as long as most assistive devices are distributed through medical systems and financed largely through public reimbursement. O'Day and Corcoran (1994), in a review of the system, stated that the acquisition of assistive technology in the United States presents many problems, including lack of funds to purchase equipment, no centralized information and evaluation system, fraud and abuse by some providers and denials of needed equipment by third party payers despite the gains made in public policy in that country.

Professionalization of Assistive Technology

Professional dominance has had an impact on the allocation of disability resources (Seelman, 1993). The Office of Technology Assessment in the United States of America found that the assessment of need for technology is most often based on perceptions of professionals or program administrators rather than through consultation with the consumers themselves. (Kohn, Mortola, & LeBlanc, 1991). Phillips and Zhou (1993) surveyed 227 adults with disabilities from various states in the United States and found that whether or not the consumer's personal opinion was considered in selection was one of the important predictors of device abandonment. Systemic problems related to device abandonment identified in a study involving persons with rheumatic disease included incorrect prescription, lack of instruction, delays in receiving devices, and lack of awareness of options (Rogers and Holm, 1992). Studies documenting the professional and bureaucratic nature of the assistive technology system could not be found, however, the need for change has been identified in commentaries from researchers in the United States (McKnight, 1988; Gradel, 1991; McNaughton 1993). Phillips and Zhou (1993) suggested a collaborative consumer-oriented model and further suggested an Independent Living paradigm approach to service delivery.

Summary

The literature review has highlighted several areas. There is a link between living independently in the community and the use of assistive technology. The Independent Living movement advocates the rights of persons with disabilities over their functional limitations. If it is assumed that assistive technology is important to independent living,

any barriers to its delivery will have a negative impact on independent living. Some possible barriers in the system that have been identified in this literature review include: negative public attitudes, lack of access to the technology, complicated eligibility requirements, costs, multiple jurisdiction over assistive technologies and medical model service delivery including professional dominance. However, it must be noted that none of these areas have been thoroughly examined with the consumers themselves.

There has been virtually no cross-disability research examining the consumer with a disability's perception of assistive technology service delivery in Canada. As Kohn et al (1991) pointed, out a key missing link across all types of service delivery is the assessment of the extent to which interventions have impact on the lives and needs of consumers. Thus the intent of this research is to fill this gap in assistive technology and Independent Living movement research. It explores the consumer perspective of the delivery of assistive technology in Manitoba to determine what it is like to be a receiver of these services and if this service delivery embodies Independent Living principles.

CHAPTER 3: INITIAL CONCEPTUAL FRAMEWORK

The literature review revealed that the delivery of assistive technology is influenced by a wide range of factors. To ensure that the study objectives were addressed in a comprehensive manner and that the interview guide reflected both the current knowledge in the field as well as the identified gaps, a conceptual framework was developed prior to data collection. The primary function of this framework was to summarize the apparent themes in the literature review and to provide a guide from which to develop and choose interview questions. The framework was an attempt to reflect the relationship of the respondents' experiences within a broader socio-political context, and to recognize the interactive nature of personal and structural resources regarding the delivery of assistive technology from the consumer perspective. This framework was based on the literature review and the investigator's personal experiences. No attempt was made at the outset to make any directional linkages since relationships between the individual variables could not be postulated before data collection was undertaken.

The initial conceptual framework was as indicated in Figure 1 on page 31. It is a model of environmental influences on the consumer who needs and uses assistive technology. The consumer with a mobility or agility disability requires assistive technology to live independently in the community. There are many environmental factors that influence the acquisition, use and maintenance of assistive technology which can be enablers or barriers to the process.

There is a current explosion of new and more assistive technologies in a

marketplace influenced by a strong consumer demand for convenience, personal choice, continuity, and courtesy. The influence of the Independent Living philosophy including the ability to make choices, to take risks, to participate in decision making, to have control over one's life and to participate in the community also factors into the situation.

Other possible barriers or enablers include the bureaucratic, political and historical organization of the delivery of assistive technology in Manitoba and relationships between professionals and vendors. Over-riding all of these barriers and enablers are societal attitudes, the accessibility of the built environment and laws related to assistive technology.

What impact these factors had on the experience of those interviewed was unknown at the outset of the study. The primary research questions were therefore: Which of these was relevant to these study participants? Which are enablers and which are barriers? What relationships do these factors have to Independent Living principles?

This conceptual framework guided the process of this study from its design and implementation through to data collection and analysis. An existing model also assisted in the data analysis and will now be discussed.

The Individual and Environmental Determinants of Handicap Situations and Social Participation Model

The investigator found the Individual and Environmental Determinants of Handicap Situations and Social Participation Model (Whiteneck & Fougere, 1996)

also useful as a framework for data analysis. This disablement model uses environmental variables as one of the main factors to explain social participation outcomes of the individual with a disability. One environmental variable discussed is assistive technology.

The purpose of this model, which was developed by the Canadian/Quebec Society for the Classification of Impairment, Disability and Handicap, is to provide a disablement model which goes beyond the present World Health Organization's (WHO) International Classification of Impairment, Disability, Handicap (ICIDH) (Woods, 1980). This model has been developed in consultation with organizations of persons with disabilities. In fact one of the authors, Dr. Patrick Fougeyrollas, an anthropologist, has a disability himself.

Two of the major criticisms of the present WHO ICIDH are its implied linear causalities of the disablement process and the lack of recognition of the environment as an important contributor to the disablement process (Whiteneck & Fougeyrollas, 1996). A number of environmental factors can facilitate or constrain an individual who has a disability. These factors include the built environment, policies, laws, climate, and the social environment. These factors interact with the individual's disability and personality characteristics. If they constrain the individual they are said to create a "Handicapped Situation"; if they facilitate, they are said to create "Social Participation" for the individual (See Figures 2 & 3, pages 32 and 33). The authors point out that it is only through the examination of the unique impairments and abilities/disabilities of a given individual, interacting with his/her unique personal identity, and with the unique environmental factors which he/she faces, that particular handicaps can be understood.

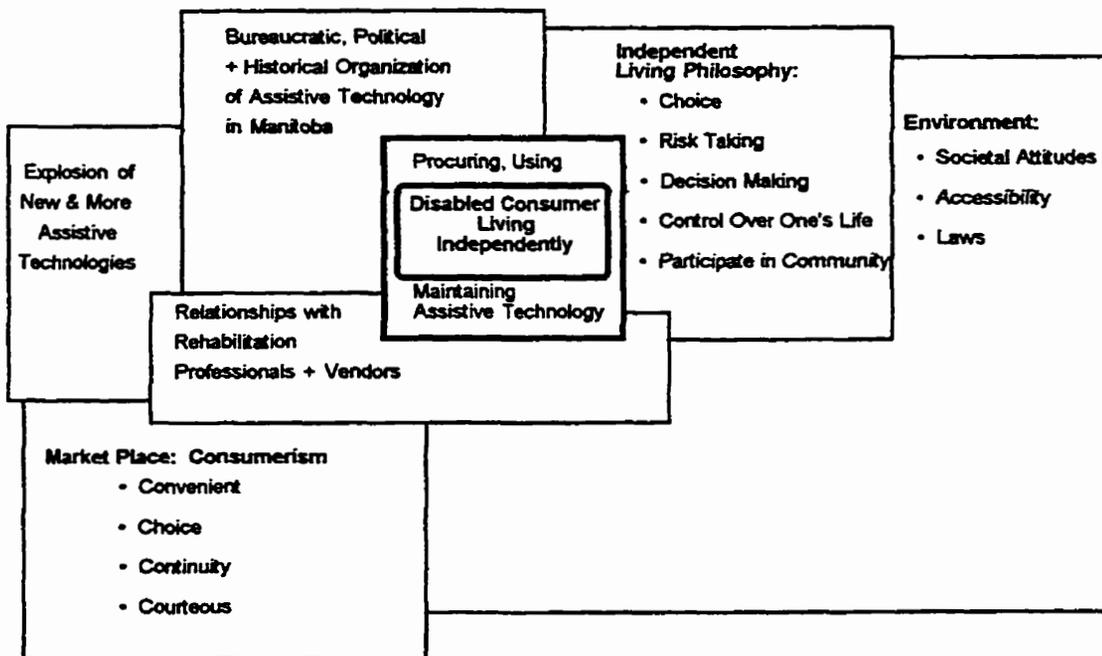
The authors also suggest three levels from which to analyse the environment. The

The authors also suggest three levels from which to analyse the environment. The "micro range" recognizes the immediate personal environment of the individual with the focus on physical and functional characteristics; the "meso level" considers a somewhat broader community environment and focuses on the attitudes and beliefs held by people which the individual encounters; the "macro level" encompasses broad societal environment focusing on policy issues. As well, five characteristics of environments, which influence how poorly or how well an individual becomes an active productive member of society, have been proposed. These include Access, Accommodation, Resource Availability, Social Support, and Equality. A chart providing examples of these characteristics combined with impairment groups with resultant environmental factors is provided in Figure 4 (page 34). This chart is taken directly from Whiteneck's and Fougeyrollas' (1996) document. (Written permission has been provided for use of all these Figures, see Appendix A-1) How this model was used in analysis will be discussed in Chapter 6.

Summary

In summary the initial conceptual model developed by the investigator was used to guide the data collection process and portions of the data analysis. The existing Individual and Environmental Determinants of Handicap Situations and Social Participation Model (Whiteneck & Fougeyrollas, 1996) provided a framework for other portions of the data analysis.

Figure 1
Initial Conceptual Framework



Model illustrates how the disabled consumer's ability to live independently is embedded in broad social constructs. Barriers + Enabling factors will affect the individuals' ability to live independently.

FIGURE 2

DETERMINANTS OF HANDICAP

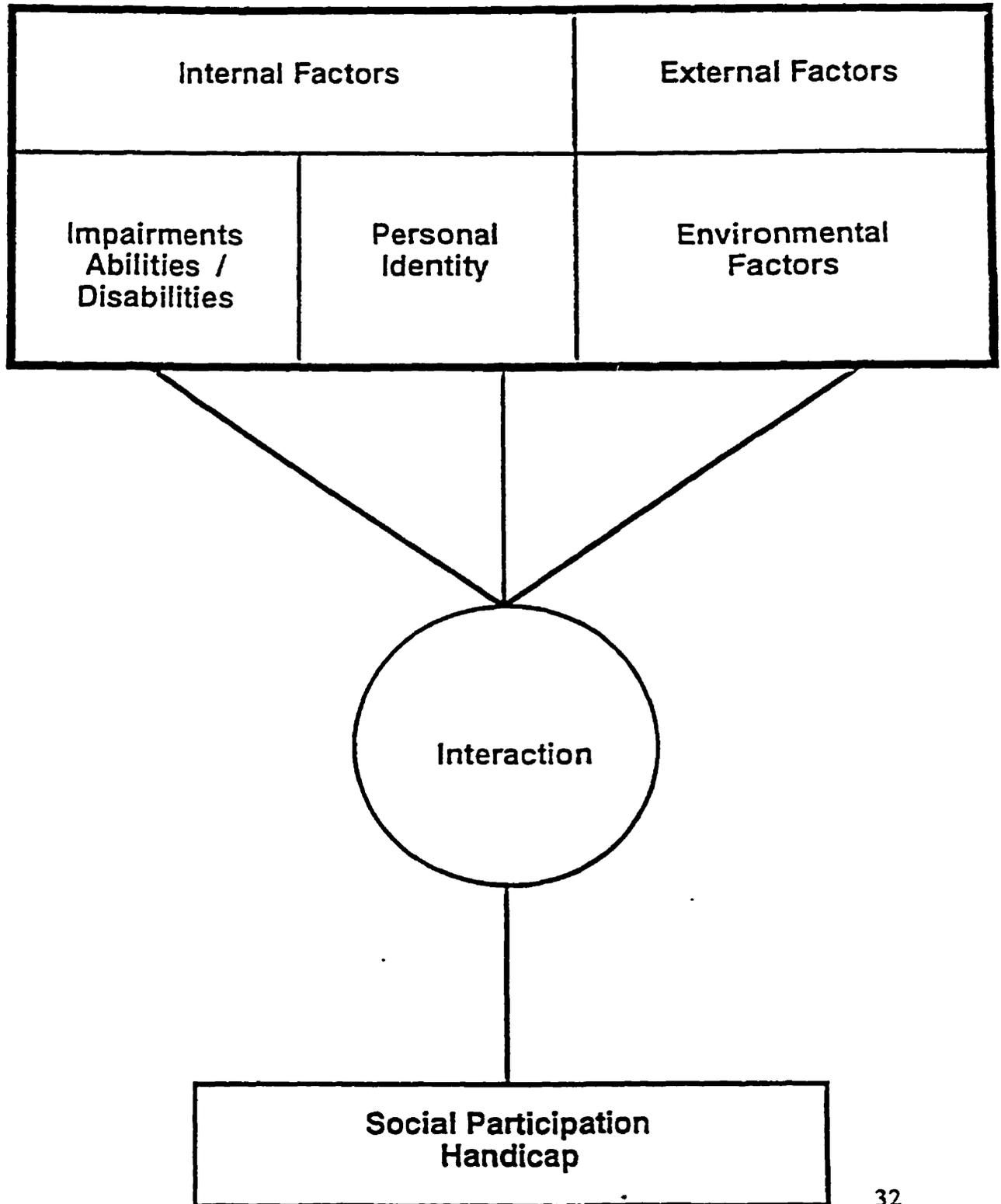


FIGURE 3

THE INDIVIDUAL AND ENVIRONMENT DETERMINANTS
OF HANDICAP SITUATIONS AND SOCIAL PARTICIPATION
(FOUGEYROLLAS P. 1995 - ADAPTED FROM FOUGEYROLLAS P. 1994)

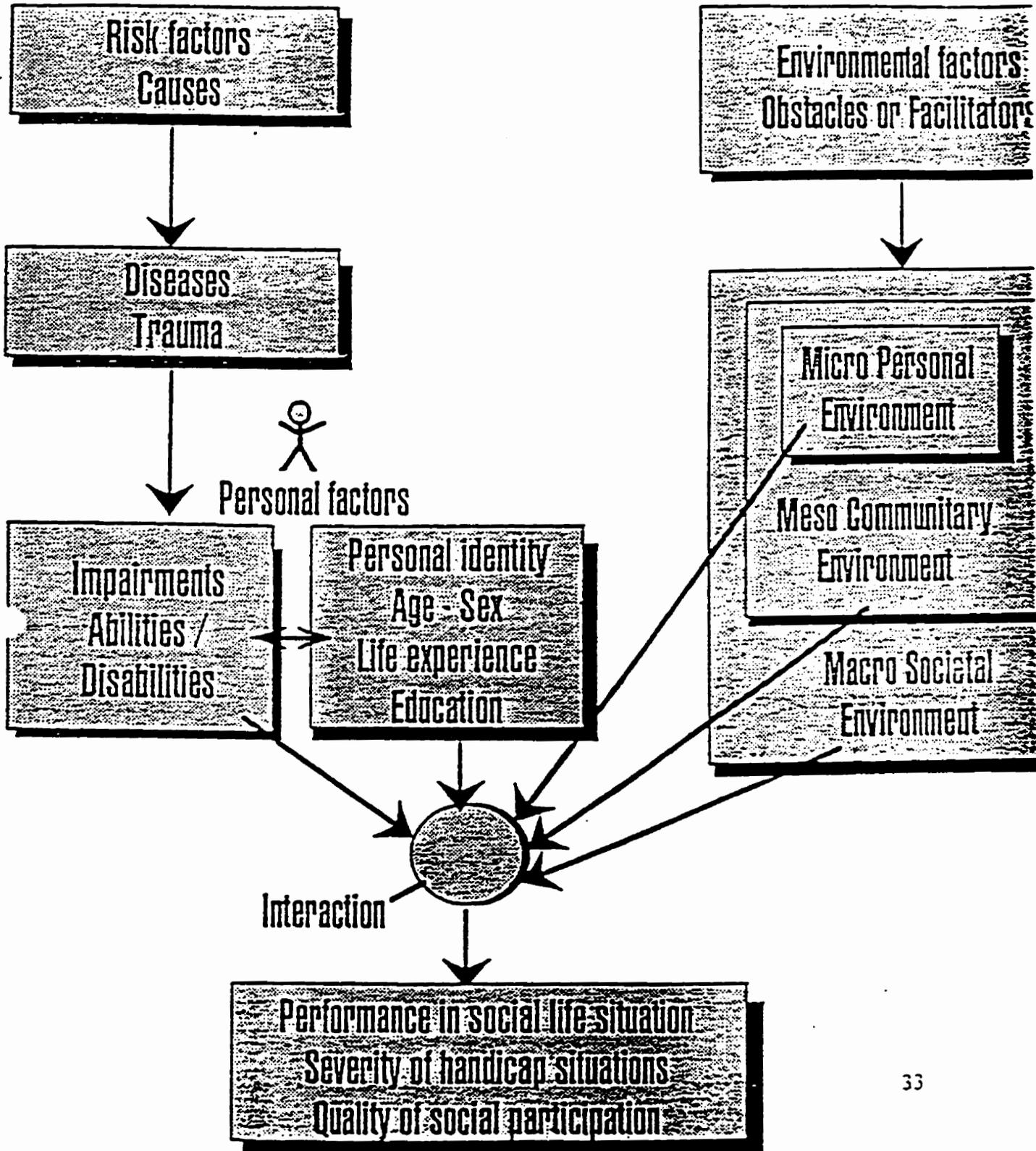


FIGURE 4
EXAMPLES OF ENVIRONMENTAL FACTORS BY ENVIRONMENTAL CHARACTERISTICS AND IMPAIRMENT GROUPS

Whiteneck & Fougeyrollas (1996)

	Spinal Cord Injuries & Mobility Impairments	Elderly People w/Strokes & Shular Impairments	Blindness & Visual Impairments	Deafness & Hearing Impairments	Cognitive Impairment - Mental Retardation, Learning Disabilities
ACCESS	ramps; elevators; wide doors; modifie	short walking distances; vertical travel rather than horizontal (ie, elevators); motorized carts at grocery stores; grab bars	braille markings on elevators; "walk" signs that beep as well as flash; directory assistance to use telephone book	does a hearing aid provide access or accomodation? (my experience is less here, but my sense is that issues melt with "acomodation" issues-- see below)	universal symbols rather than words on road signs; user friendly computers; (also seems to be overlap with accomodation -- see below)
ACCOMODATION	modified work stations; flexible hours; parking	home health care givers to assist spouse and avoid nursing home placement; shorter work day; provide perceptually uncluttered environment	reading machines; talking calculators; improved lighting; large print; allowing assistance dogs or accompany indoors	interpreters; close captioned TV; fire alarms, doorbells, phones that flash as well as ring	special education; supervised work environments; simplified written instructions
RESSOURCE AVAILABILITY	attendant care; trial work programs; income continuation	early retirement; pension programs; respite for spouse	cheap & available trained guide dogs; income support; vocational retrain; home makers and other non-medical assistance in the home	interpreters pools; training programs for interpreters; income support; cheap, easy availability of hearing aids and other technologies	\$ for supportive care; available group homes & other non-institution support options; respite care for families; support groups for families
SOCIAL SUPPORT (what we've provided here are the biases and negative attitudes)	change belief that death better than SCI; change belief that disability= sickness; mis-perceptions about quality of life	change belief that stroke= cognitive damage. Old people shouldn't be using up limited resources	"Blind as a bat" Blind people get unfair share of reources (special income tax deduction)	deaf=dumb or stupid; Deaf people shouldn't drive; belief that deaf people need special sports options rather than accomodation by ablebodied sports	mentally retarded people are incompetent in all areas. People with learning disabilities are not intelligent
EQUALITY OF OPPORTUNITIES (most all of these issues transcend disability groupings)	equal employment opportunity; ADA; mandated accessible transportation; higher health insurance premiums; hogher auto insurance premiums	denial of life insurance due to pre-existing condition	belief that can't work because blind; most of world is designed for sighted persons. Access at national parks, museums, etc adresses mobility, but not vision	closed captioned TV & films not universal; open captions rare; political controversy regarding lip reading and speaking versus signing	mandated educational main streaming; laws guaranteeing access to education; forced sterilization; belief that persons with Mit are unfit parents

CHAPTER 4 - RESEARCH DESIGN: METHODOLOGY, METHODS, AND IMPLEMENTATION

A qualitative approach was chosen for this study because of the need to document the individual's experience with the delivery of assistive technology and to identify relevant variables. Marshall and Rossman (1989) describe these two reasons (the individual perspective and identification of variables) as critical in choosing a qualitative approach. It is important to explore the frame of reference of a consumer with a disability and this can only be done adequately through qualitative methods such as the in-depth interview.

Specifically, critical ethnographic methodology was chosen because the personal experience of the health-care system cannot be considered in isolation from the social, cultural and political context in which people find themselves (McLean, 1990). Critical ethnography refers to the reflective process of choosing between conceptual alternatives and making value-laden judgements of meaning and method to challenge research, policy and other forms of human activity (Thomas, 1993). According to Thomas (1993), critical ethnographers use their work to aid emancipatory goals or to negate the repressive influences that lead to unnecessary social domination of all groups.

Another name for this methodology is "institutional ethnography" as described by Smith (1987). She discussed how systemic forces, which are not evident to people, can exert powerful control over their lives. By making these forces explicit, it becomes possible to change social relations to create a more equitable situation.

This approach is important since a critical ethnography of the assistive technology system could not be found in the literature.

Time Line

The time line for the study is shown in Appendix J. Interviews were carried out between November 1994 and February 1995

Sample Selection

Inclusion Criteria

The following criteria were applied selection of informants:

- urban dwelling (Winnipeg, Manitoba)
- adult (>18 yrs to <65 yrs)
- mobility disability
- may have an agility disability

Exclusion Criteria

To ensure homogeneity in the disability and assistive technology service utilization experience, the following exclusion criteria were applied.

- those with significant hearing or visual impairment
- seniors and children
- rural residents

The researcher chose to include in this sampling only people in Winnipeg because of their availability to her (a sample of convenience) as well as the fact that there would be an anticipated difference of experience with rural dwellers. She also decided to interview both those who had been involved with the Independent Living philosophy and those who

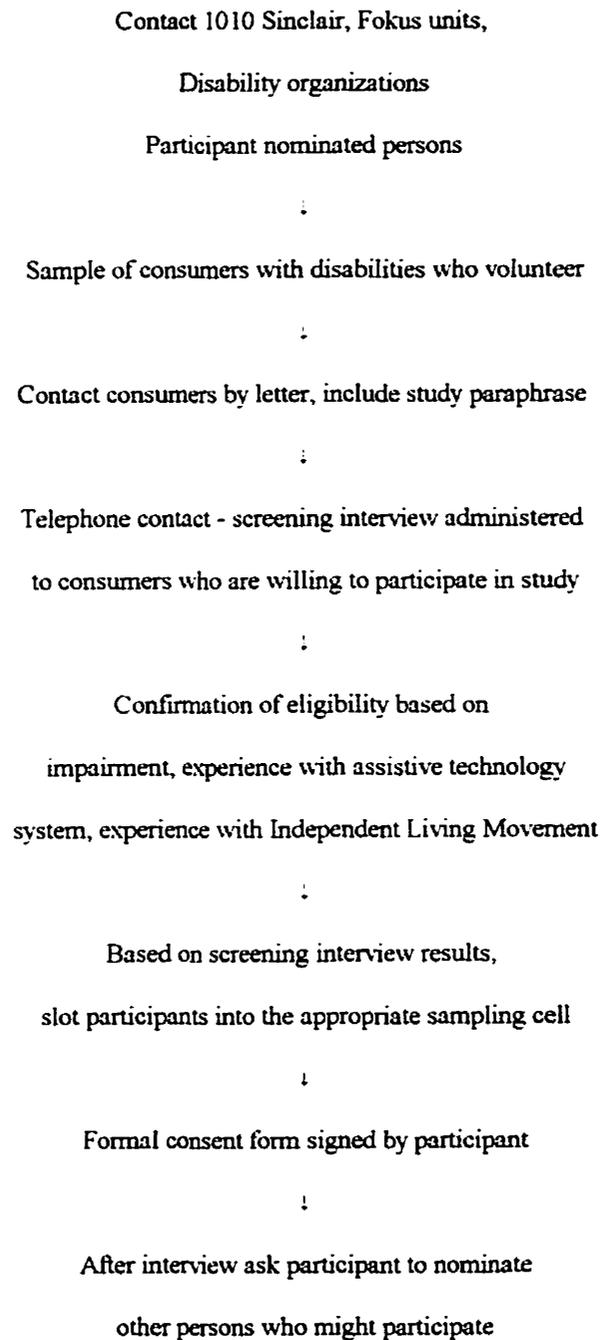
had not been directly involved.

Sample Selection Methods

There were three methods of sample selection involving three groups of people interviewed. These were non-IL involved (approached through contacting Fokus Housing, Riverside Lions Estates and the Canadian Paraplegic Association); IL-involved (contacted via various disability organizations); and subject-nominated sampling also called snowball sampling (reached by asking interviewees to provide names of other potential interview candidates). Figure 5 is a flowchart of the sampling process.

FIGURE 5

Flowchart Summary of Sampling Process



Sample Selection Groups

Sample: Non-involved In Independent Living (II) Movement

One sample was drawn from two congregate disability housing facilities in Winnipeg, Manitoba: Ten Ten Sinclair transitional living housing and Fokus housing. It was hoped this method would provide a mixture of individuals both new to and familiar with the assistive technology system. (See Appendix A for explanation of Ten Ten and Fokus housing). Consumers, living in these environments, usually have a significant level of disability that would require some sort of assistive technology. Halfway through the study, it was decided to contact another facility - Riverside Lions Estates - which had a high number of residents with disabilities. Permission was obtained to place a poster in the lobby of this apartment block advertising for study participants. Only one person responded. The Canadian Paraplegic Association was also contacted for assistance. They were able to provide two names of people who did volunteer to participate (See Appendix B).

Sample: Highly Involved In Independent Living (II) Movement

Through reviewing the staff and volunteer lists of various disability consumer organizations in Winnipeg, Manitoba including the Independent Living Resource Centre, Disabled People International, Manitoba League of the Physically Handicapped, Canadian Paraplegic Association and the Council of Canadians with Disabilities, names were chosen and people approached about participating in the study. (Appendix B) It was presumed

that valuable information could be gained from key individuals who hold executive, staff or committee positions in disability organizations and who can provide an informed viewpoint on the subject. These individuals could also report on their organizations' past histories, policies and future plans regarding assistive technologies.

A consumer with a disability, who is highly involved in the Independent Living movement, was presumed for the purposes of this study to

- 1) occupy a leadership position or be employed with a disability organization
- 2) have experience with the assistive technology delivery system, as determined by answers to questions during interview.

Subject-Nominated Sampling Technique

After one interview of each subject in both groups, the individual was asked if he/she knew of someone who would be interested in being a participant in this study. These individuals were then contacted by phone or by mail and provided with the same information given to other individuals in the study. Subjects were assigned to either the IL involved or non-involved groups, based on the earlier definition. Individuals who qualified for the IL non-involved group did not have to live in Ten Ten Sinclair or Fokus housing.

Access to Respondents

After approval from the University of Manitoba Faculty Committee on the Use of Human Subjects in Research, a formal request to access residents at the Ten Ten Sinclair, Fokus Housing and at Riverside Lions Estates was made (See Appendix B). Eligibility

was described in the letter to the managers and then repeated in the screening interview questions. The same letter was sent to individuals involved with disability organizations to enlist persons who are highly involved in the Independent Living Movement (Appendix B). Included with these letters was the study's paraphrased statement (Appendix C). The contact letter stated that the potential participants would receive a follow-up telephone call within one to two weeks to determine their interest in participating in the study.

The individuals were asked if they would consent to answering a screening interview (Appendix D) over the telephone. Provisions were made for the potential participant, if uncomfortable answering the questions over the telephone, to be interviewed in person. This did not occur. Individuals who did not wish to participate in the study would not have been asked to complete the screening questions. Again, this did not occur. Based on the responses to the screening interview, individuals were informed whether or not they were eligible to participate in the study. Those who did not meet the criteria were excluded from the study and their screening interview data and personal information was destroyed. This possibility was explained to the individual prior to the administration of the screening interview questions. If accepted into the study, the final aspect of this telephone call was to set up a meeting to sign a formal consent (Appendix E). Once again, the potential participant was told that agreeing to participate in the study would mean being interviewed. Every reasonable effort was made to ensure that there was a witness to the signing of the consent. However, this was not always possible.

Phases in the Methodology

There were four phases including three overlapping phases and one final phase involved in this methodology (See Figure 6).

- 1) In-depth semi-structured interviews with Independent Living Movement non-involved consumers with disabilities
- 2) In-depth semi-structured interviews with Independent Living Movement involved consumers with disabilities
- 3) Descriptive Profile of the Delivery of Assistive Technology in Manitoba
- 4) A final phase of the study will be to bring together in a forum the persons interviewed in phases one and two to discuss the results and to validate the analysis. Participants can then use the information to assist in lobbying efforts if desired. This last phase is a recognized technique in critical ethnography (Thomas, 1993). This will occur outside the context of this thesis.

Figure 6

Phases in the Methodology

Phase 1: Non-Involved in Independent Living Movement Interviews
Core Interview: Personal Experiences
Indirect Exploration of IL Principles

Phase 2: Highly Involved in Independent Living Movement Interviews
Core Interview: Personal Experiences
Direct Exploration of IL Principles

Phase 3: Descriptive Profile of the Delivery of Assistive Technology in Manitoba
Review of Official Documents
Literature Review
Interviews with Highly IL Involved Consumers

Phase 4: Forum

Phases (1) and (2): Interview Procedures

A series of semi-structured in-depth interviews with IL non-involved and involved consumers with disabilities was carried out. Interviews were approximately 1 - 1 1/2 hours in duration. All interviews were audio-taped and then transcribed. A record of all interviews was kept (Appendix F). Each individual was asked three sets of questions (see Appendix G). These included the (A) Background Questionnaire, (B) The Core Interview, and the (C) Specific questions for either the IL non-involved or involved individuals.

Background Questionnaire

Prior to the interview, each person was given a background information questionnaire to document basic demographic characteristics. (Appendix G-1)

Core Interview

The core interview was given to both groups and centred around their own experience with the delivery of assistive technology. Topics covered in Appendix G-2 were discussed. The questions listed served merely as a guide for the researcher with some questions omitted or expanded upon depending upon the direction taken by the interview. Participants were allowed to expand on their own experiences and perceptions.

Specific questions for the IL non-involved individuals with disabilities

These questions were designed to explore indirectly the way these individuals

approach the assistive technology delivery system (described below) in terms of what is advocated in the Independent Living philosophy. For instance, one question was "If a professional told you that you could not have a piece of equipment and you felt you should have it, what would you do?" The added questions for this group are listed in Appendix G-3.

Specific Questions for the IL-involved individuals with disabilities

The additional questions for this group were designed to explore whether or not Independent Living principles were evident during their experience with the system. For instance, "Did you feel you were given control over choices regarding assistive technology?" It was hoped that the respondents would understand this type of terminology as expressing Independent Living principles. The added questions for this group are listed in Appendix G-4.

Phase 3: The Assistive Technology System Descriptive Profile

A description of the assistive technology system in Manitoba was developed including methods of funding, personnel, laws and policies, and methods of access. This was related to the larger societal and political environment in which the Manitoban assistive technology system is situated.

This description was developed through several information sources including review of official documents, review of lay documents, and the interviews with consumers highly involved in the Independent Living Movement. This policy and system review helped in understanding the environmental/cultural context of the consumer's experiences.

Requests for information were sent to the Home Care Equipment Pool and to Rehabilitation Engineering Services. (Appendix K)

This review was necessarily limited because of the defined scope of a Masters thesis. It is understood that a more in-depth profile should be generated in a comprehensive critical ethnography. However, this was beyond the scope of this project.

Phase Four: Consumer Forum

All persons interviewed from Phases 1 and 2 will be invited back to a forum where results of the analysis will be discussed. They will be sent a letter of invitation to participate (Appendix H) with the understanding that they are under no obligation to do so even though they have already participated in the interviews. The forum is a recognized method of critical ethnography not only to ensure trustworthiness of the of the study, but also to allow the participants a springboard for future action should they wish to take it (Thomas, 1993). This forum will occur after the thesis defence.

Managing and Recording Data

Interviews were recorded and coded using Word Perfect for Windows (6.1A) word processing software. Interviews were stored both in audio-tape and hard-copy format. Confidentiality was protected by identifying transcripts, audiotapes and questionnaires by numbered codes rather than by participant names. The master list of names and codes was kept separate from the study data.

Data Analysis Strategies

Data obtained from interviews were coded thematically, indexed, and any common themes extracted. Following each interview, preliminary analysis of the data occurred to determine any connection with the literature or any emerging patterns from the analysis of previous data. It was hoped that this preliminary analysis would increase the efficiency of data collection and analysis. A “Contact Summary Form” (Appendix: I) described by Miles and Huberman (1994) was prepared after each interview. This became the main method of coding, indexing and later extracting themes.

The Strauss and Corbin Paradigm Model

To assist further in the analysis of the data, the investigator decided to use the Paradigm Analytical Model suggested by Strauss and Corbin (1990). This model is intended to assist the researcher in moving towards an inductive approach to the material. This is a method of axial¹ and selective² coding suggested by the authors. The focus becomes one of relationships, connections and context which serve to enhance the density of analysis and the precision of the generated hypothesis.

In the Paradigm Model, Strauss and Corbin (1990) link sub-categories to a category in a set of relationships denoting causal conditions, phenomenon, context, intervening conditions, action/interactional strategies, and consequences. These are

Axial Coding: A set of procedures whereby data are put back together in new ways after open coding, by making connections between categories. This is done by utilizing a coding paradigm involving conditions, context, action, /interactional strategies and consequences (Strauss & Corbin, 1990, p.96).

Selective Coding: The process of selecting the core category, systematically relating it to other categories, validating those relationships and filling in categories that need further refinement and development.(Strauss & Corbin,1990, p.116)

defined in Table 2 (page 52). The analytic process follows a logical sequence in which a core category is chosen first. This is termed the phenomenon. Then sub-categories are linked to the phenomenon in the following way: A (conditions) lead to B (the phenomenon), which occurs within C (context), impacted on by D (intervening conditions), leading to E (actions/interventions) and resulting in F (consequences) relating to the core category. Strauss and Corbin (1990) believe that this is the only way to develop a theory for the data presented.

They cautioned that this model should not be confused with a linear model as the analysis occurs in a dynamic fashion, recognizing that no step occurs in isolation or without having an impact on others. This process insures that a systematic approach is utilized as the data from the interviews are grouped and integrated. It also provides a framework for the researcher to explore occurrences that do not appear to fit within the emerging themes.

In this study the model was used to assist the researcher to frame the data and provide a descriptive model for understanding the common themes among the respondents. The core category of “Acquiring Assistive Technology Needed for Independence” arose not only from the grounded theory of the paradigm model but also through the initial design and direction for interviewing. This core category then provided a focal point around which the other emergent categories were integrated into the analysis. A process of contextualization described by Denzin (1989) then occurred where what has been learned about the phenomenon is fit back into the social world where it occurs. A critical analysis of this social world was carried out as suggested by Poland

(1992). Through the process of grounding the core category and its contributing features within a socio-political context and consideration of conditions and consequences, a working theory was induced. This theory will be presented in Chapter 9 in the “modified conceptual model” section.

The paradigm model described by Strauss and Corbin (1990) along with the categories determined in this study are illustrated in Figure 7 on page 53. Each category will be described in the following chapters.

Trustworthiness of the Study

To ensure trustworthiness, a process of triangulation occurred. This was achieved through the interviews, a review of historical documents and interviews of key individuals as well as what will be accomplished through the process of the final forum. My advisor for this thesis also reviewed the transcripts and themes and either agreed on themes or offered suggestions for further themes. The draft thesis was also given to two of the study participants for comments.

Management of the Researcher Role

In many respects, I can be considered to be an "insider" in this research for the following reasons:

- I am known to many of these individuals due to my involvement on various committees of disability groups
- I know some people in management positions at Ten Ten Sinclair and Fokus
- I am an occupational therapist who has an assistive technology private practise

- I keep up to date on consumer issues related to assistive technology through my membership with RESNA
- I have a disability myself which can be an advantage for entry into this community

It was an advantage for me not to have previously known everyone who volunteered for the interview from the non-involved group. I am fully aware that many of the insider roles that I have can be an advantage. However, I am also aware of the dangers of being an insider and made every attempt to guard against my own bias in this project. As well, I attempted to probe for information from the participants even when these persons assumed I knew what they were talking about.

Ethical Considerations

Approval from the University of Manitoba's Faculty Committee on the Use of Human Subjects in Research was obtained in July, 1994. Formal requests for entry were made to Ten Ten Sinclair, the Fokus units, Riverside Lions and the Canadian Paraplegic Association. Individual letters were sent to recognized leaders in disability organizations.

Informed written consent was obtained from all participants. Each participant was told that participation in the study was voluntary and that he or she was free to refuse to answer specific questions or to discontinue at any time.

Confidentiality was protected by identifying transcripts, audiotapes and questionnaires by numbered codes rather than by participant names. The master list of names and codes was kept separate from the study data.

As much as possible, descriptive information that would lead to identification of a participant does not appear in any report. However, it was acknowledged to the participants that, due to the relatively small population of persons with disabilities in Winnipeg and due to the familiarity of many of the highly involved consumer personalities, it is possible that some of their information may be recognizable. To alleviate some of this difficulty, identities were masked through the use of pseudonyms and composite data aggregation, and, when necessary, the direct permission to use information and quotations from consumers once the data were aggregated.

Table 2

DEFINITIONS OF TERMS IN STRAUSS AND CORBIN PARADIGM MODEL

(Strauss & Corbin, 1990)

CAUSAL CONDITIONS - events, incidents, happenings that lead to the occurrence or development of a phenomenon.

PHENOMENON (CORE CATEGORY) - the central idea, event, happening, incident about which a set of actions or interactions are directed at managing, handling, or to which the set of actions is related.

CONTEXT - the specific set of properties that pertain to a phenomenon, that is, the locations of events or incidents pertaining to a phenomenon along a dimensional range. Context represents the particular set of conditions within which the action/interactional strategies are taken.

INTERVENING CONDITIONS - the structural conditions, bearing on action/interactional strategies that pertain to a phenomenon. They facilitate or constrain the strategies taken within a specific context.

ACTIONS/INTERVENTIONS - strategies devised to manage, handle, carry out, respond to a phenomenon under a specific set of perceived conditions.

CONSEQUENCES - outcomes or results of action and interaction.

Figure 7

THE PARADIGM MODEL RELATED TO STUDY FINDINGS

Causal Conditions (Chapter 5)

Agility/Mobility Disability

Phenomenon: Core Category (Chapter 5)

Acquisition of Assistive Technology Needed for Independence

Context (Chapter 5)

Assistive Technology Acquisition Methods

Government Sponsored

Insurance

Vendor

Mixed

Intervening Conditions (Chapter 6)

Barriers and Facilitators For Getting Assistive Technology

Information Sources

Cost/Eligibility Requirements

Bureaucracy

Choice

Relationships with Professionals

Relationships with Vendors

Accessibility of the Built Environment

Strategies for Getting Assistive Technology (Chapter 7)

Play the Game

Peer Support

Resource Network

Invention

Peers Support

Speak Up

Consequences of the Strategies (Chapter 8)

Chapter Five

CHAPTER 5 - RESULTS: THE CORE CATEGORY, THE CONDITIONS, THE CONTEXT

This chapter of results presents the analysis of the data in relationship to three categories of the Strauss and Corbin (1990) model: 1) core category, 2) conditions, and 3) context. Use of this model as an analytic framework provided the investigator with a systematic method of developing a grounded theory.

The Core Category

The core category for this study has been given the title "**Acquisition of Assistive Technology Needed for Independence**". The core category or phenomenon is defined as "the central idea, event, happening, incident about which a set of actions or interactions are directed at managing, handling, or to which the set of actions is related" (Strauss & Corbin, 1990, p.96).

While there may be more than one core category found within the data set, Strauss and Corbin stressed the importance of dealing with one, and only one, core category at this level of analysis.

“ ... a decision as to the central phenomenon is crucial to the study. The central phenomenon is at the heart of the integration process. It is the essential cement in putting together-and keeping together - all the components in the theory” (Strauss and Corbin, 1990:124).

The selection of "**The Acquisition of Assistive Technology Needed for Independence**" as the core category was based on the initial question going into the interviews and the main topic on which all participants focused. Although the initial question focused on

“What is your experience with the delivery of assistive technology in Manitoba”, the participants expanded on it and discussed how important it was to acquire the equipment (assistive technology) to allow for independence in their lives. The researcher could then fit other themes into the categories of context, intervening conditions, strategies and consequences which seemed to relate well to the chosen core category.

Why Acquisition of Assistive Technology is Important for Independence

Assistive technology is one aspect of the life of the person with a disability. However, it is a very important aspect in North America. There has been a technology explosion in society in general: remote controls to operate televisions and garage doors, computers, electronic mail, and fax machines are commonplace items in the 1990s. Many of these items could be considered luxuries, since people could still function, albeit, perhaps less efficiently without them. However, to a person with a disability in North America, where the expectation is, given the proper resources, the individual can be self-sufficient in all aspects of life, assistive technology is not a luxury. It is a thread woven into the fabric of life. If this thread is missing, the ability to live independently is weakened.

The following excerpts illustrate the meaning of assistive technology in various participants' lives: *"If I didn't have my wheelchair I wouldn't be able to go out, walk to work and walk home. I wouldn't have a job (.001.IL p.8).*

The following person explains how important even relatively simple devices are to her functioning:

I would buy a can opener just like every other person would buy a can opener, it's going to mean a lot more to me than it would be to an able bodied person and it's going to be more important for me to choose a specific can opener as compared to a lot of other people... We're not talking special as in luxury,.. I think everyone else in the free world can do it, why shouldn't I? (.001.IL p.9 478-496)

Having the appropriate assistive technology means the difference between living in the community or living in an institution to the next participant:

It always bothers me when people can't [get what they need] because the things that I use are so important to me and I've got to have them. I couldn't live here without the power chair and the TOSC. [environmental control unit] I'd be in a nursing home some place, that's the difference it makes in my lifestyle now. Lord knows how many other people just haven't had the good fortune I've had (.008.NIL p.9).

The next respondent had explained in her interview how a scooter was more beneficial to her than a power wheelchair because she felt it allowed her to keep her back muscles strong so that she could participate in other activities.

As I said the scooter was the best thing that happened to me, ... I can still get into a canoe and canoe, I can still ride on a snowmobile behind somebody, and those experiences in life is the reason why I'm able to ride the scooter too (011.NIL p12).

The following respondent described the psychological and social impact of a manual versus a power wheelchair.

The solution of a back-up to a manual wheelchair user is quite effective but to a power wheelchair user, someone not able to really be mobile with a manual chair, when your power chair breaks down in the early part of a weekend, you're really immobile for the rest of the weekend until office hours [of the Wheelchair Repair Service] open again, and that's a terrible cost personally. You have to rely on someone else to push you around (012.IL p7-8).

These excerpts from the participants' narratives illustrate the importance of the

technology to their lives. The individuals discussed how technology is important to functioning, participation in meaningful activities, to eligibility for living arrangements and to their standard of living. One individual described assistive technology as a necessity not a luxury.

Causal Conditions

According to Strauss and Corbin (1990) the "Causal Conditions" of the paradigm model refer to:

the events or incidents that lead to the occurrence or development of a phenomenon. For example, if interested in the phenomenon of pain, we might discover that breaking a leg or having arthritis can lead to pain (p. 100)

In this study, causal conditions will be discussed in terms of the demographic and disability-related variables influencing the experience of individuals interviewed and how these factors in turn influence their need for assistive technology. This will include age, type of disorder, onset of disability, level of disability, sampling source, type of residence, employment status, use of an attendant, highly involved versus not highly involved in the Independent Living Movement, length of time using assistive technology, type of assistive technology used and main assistive technology source.

As described previously, this sample was drawn from a variety of sources including disability organizations, Fokus Housing, Riverside Lions Housing, Canadian Paraplegic Association, and Snowball sampling. Seventeen urban dwelling adults with both mobility

and agility impairments were interviewed. All had agility as well as mobility impairments.

Age Range

Exact age was not requested, however age-range data demonstrated an age range for the sample between 26 and 65, with twelve out of the seventeen individuals between 46 and 55 years. Age of onset of their disabilities ranged from birth to adulthood.

Reasons for Disability

Reasons for disability included Polio: 6; Spinal cord injury: 4; Spinal Muscular Atrophy: 2; Rheumatoid Arthritis: 1; Cerebral Palsy: 1; Brain Injury: 1; and Multiple Sclerosis: 2. Individuals had either been born with their disability (1) or acquired it as a child (6), adolescent (4) or as an adult (6). Thus even in this small sample of seventeen individuals, there was present a variety of different disabilities and age at which the disability was acquired.

Level of Disability

Although everyone in this sample had both a mobility and an agility impairment, their levels of impairment differed. Individuals ranged from having complete quadriplegia, various levels of quadriplegia, to quadriparesis, to paraplegia, to hemiplegia, to arthritis in all four limbs.

Sampling Source

Nine people were obtained through direct letters to disability organizations. Four were obtained from the Fokus Housing, one from Riverside Lions housing, one from CPA and two from Snowball sampling.

Residence

Nine individuals live in Fokus housing, three in apartments not associated with Fokus, and five live in houses.

Use of Attendant

Three people indicated that they did not use an attendant, however one of these individuals later discussed how his wife assisted him with some of his ADL tasks.

Highly Involved versus Not Highly Involved in the Independent Living Movement

(IL versus NIL)

Nine out of the seventeen individuals were classified as IL, defined for the purposes of this study as:

- 1) having a leadership position or employed with a disability organization;
- 2) well versed in the Independent Living philosophy; and
- 3) having a wider perspective on the delivery of assistive technology due to their position in a disability organization.

Gender

Five of the seventeen individuals interviewed were females and of these, three were classified as IL.

Employment

Nine out of the seventeen people interviewed worked full-time, six were unemployed, one retired early due to disability, and one was on a leave of absence due to health problems. Individuals, who were employed, worked in a variety of occupations

including three management positions in disability organizations, three individuals who provide information, referral and counselling at disability organizations, two individuals who have senior management positions with the provincial government. One individual was an office worker at a disability organization and one was an educator. Of those unemployed, one had never worked, one had worked as a labourer which resulted in his/her injury, one had owned a private business prior to injury, one had been in the army prior to onset of the disease, one had worked in an office, one had been a homemaker and one person had worked as a health-related professional prior to retirement.

It should be noted that in the IL/Non-IL distribution related to employment: in the NIL classification, 6/8 were unemployed, while in the IL classification none were unemployed with the exception of one who retired due to his/her disability. Part of this is, of course, due to the classification method which was set up to identify IL versus NIL individuals.

Assistive Technology

Length of Time Using Assistive Technology

Time using assistive technology ranged from six to 40 years with the average time being 28.3 years. This average provides an estimate of the length of time with a disability and provides evidence that the individuals had had a considerable experience with assistive technology and its delivery system.

Main Source of Assistive Technology

For 15 of 17 individuals, the main source of assistive technology funding was the

government-sponsored program . The two remaining individuals were covered by Worker's Compensation. Two individuals also had insurance coverage.

Type Of Assisitive Technology Used

A wide variety of assistive technology used was described by these individuals in the interview. This variety included devices in the following assistive technology categories: mobility, home modifications, lifting, bathing, bed, dressing, writing/reading communication (no augmentative communication devices were included), breathing, driving, and orthotics.

The average number of assistive technology devices per person was 7.9 devices. The average of the NIL group was 7.6 and of the IL group was 8.2 devices; however, one person in the IL group skewed the results by having sixteen devices.

By far the most common type of assistive technology was mobility aids (including power and manual wheelchairs). The next most widely used types of assistive technology included driving adaptations and lifts, door openers, wheelchair cushions, reachers, body lifters and speaker phones. Three individuals were ventilator(respirator) dependent and two others used a CPAP (Continuous Positive Air Pressure) machine which may indicate that they will be ventilator candidates in the near future. This is a machine that assists in keeping the airway open at night when the individual is asleep. It is used by persons with sleep apnea, however, many people with post-polio syndrome have had to start using it with the deterioration of their condition.

It is possible that respondents may have forgotten some of the items during the interview since they take them for granted. This did happen during some of the interviews. For instance, an individual would describe his/her assistive technology but neglect to include the powerchair in which he/she was sitting until the investigator reminded them of it. Therefore, it is possible that the numbers of devices are not entirely accurate. However, the figures do provide a feel for the type of equipment the participants have.

Summary of Causal Conditions

These seventeen individuals have experienced agility and mobility disabilities as the result of birth disorder, disease or trauma. Most individuals have had their disability for several years and thus have had experience with the delivery of assistive technology. Although most are employed, they still rely on the government-sponsored program for assistive technology. Their disability requires that they use a wide variety of assistive technologies.

The Context

According to Strauss and Corbin (1990, p. 101), *context* “represents the specific set of properties that pertain to a phenomenon; that is, the location of events or incidents pertaining to a phenomenon along a dimensional range”. Describing the context enables one to understand the reasons for an individual to choose certain strategies in particular situations. In this study, the context is described from a socio-political perspective as the range of assistive technology services or “systems” available to the adult consumer in

Winnipeg, Manitoba.

Assistive Technology Service Delivery in Canada

Within the context of Manitoba Health guidelines, assistive technology is considered to be a support service. Health services are generally covered by provincial government programs in Canada which are governed by the Canada Health Act (1984) which defines five principles: public administration, comprehensiveness, universality, portability, and accessibility. (Statutes of Canada, 1993). Despite these principles, each province in Canada controls its own health care program and this results in differences in the delivery of services across Canada. The delivery of assistive technology, including what equipment is provided and what services are provided, differs across Canada. For instance, at the time of this study (1994-95), Ontario had a specific Assistive Device Program (ADP) with specific ADP vendors and service providers. Ontario consumers had a wider variety of products available to them than did the consumers in Manitoba. Traditionally, government-sponsored programs have been delivered using a medical model (where authority for decision making rests with a professional, primarily a physician), which is described in some detail in this thesis.

Trends

Manitobans have been faced with government cutbacks to their health care system similar to those in other provinces in Canada and to the states in the United States. The

rise of the disability consumer movement, increased consumer rights, increased accessibility of the built environment and the proliferation of new assistive technology professionals and vendors has happened at the same time.

Two important pieces of legislation in the United States relate to assistive technologies. The Americans with Disabilities Act (1990) is a civil rights act which guarantees equal access to and opportunities in employment, transportation, public accommodations, state and local government, and telecommunications for individuals with disabilities. Many issues of access revolve around the use of assistive technologies. The Technology-Related Assistance Act (1994) was the first federal legislation that specifically addressed expansion of the availability of assistive technology devices and services. Although there is no similar legislation in Canada, their impact spills over into this country as people expect to be treated in a similar manner.

Acquisition Patterns

Within the context of assistive technology delivery, there are four acquisition routes for adults with disabilities in Manitoba. They can:

1. rely on the government sponsored programs
2. rely on private or public insurance
3. purchase their own equipment directly from a vendor
4. use a mixture of these acquisition routes.

Because there is no coordinated approach to assistive technology in Manitoba, it could not be said that there is an assistive technology “system”. There is a variety of

acquisition routes with multiple providers, sometimes a duplication of effort, and dependent on the person's eligibility for entitlement. The following quote provides a backdrop for the present delivery of assistive technology.

There has not been a coordinated approach here for assistive devices... it's a variety and a hodgepodge of insurance, like Autopac, and private insurance companies, and Blue Cross and SMD and Canada Pension Plan and Workers Compensation and Veterans Independence Program, a myriad of other programs all approaching and duplicating the access to products based on somebody's assessment or need and entitlement, and it all gets back to whose money pays for what and therefore who controls the choices and what bureaucracy they put in place to implement those choices. So it's a very mixed up world there, all mixed up in this duplication of private and public services and who pays for what (.003.IL p11).

Each of the three discrete acquisition routes will now be discussed. However, it should be noted that very little official information was available from these sources. One is reliant on brief pamphlets or one-page documents. In the case of the Home Care program, it was very difficult to obtain any information at all. The information presented is that which was available at the time of the study (1994-95).

Acquisition Route 1: Provincial Government-Sponsored Programs

There are three government-sponsored assistive technology programs: the 1) Home Care Equipment Branch, 2) Wheelchair Services and the 3) Special Devices Program in the Rehabilitation Engineering Department, Health Sciences Centre. These are separately run programs. Occupational therapy and physical therapy assessments (4) also make up part of this "system". Formal peer counsellors (5) working at non-profit agencies will also be mentioned in this section.

Home Care Equipment Branch

The Home Care Equipment Branch is an arm of Manitoba Health. Its objectives are to provide

on loan certain types of medical equipment to facilitate the care of individuals within their own homes rather than hospitals or other types of institutions with an aim of improving the health and well-being of the population.¹

Note that all equipment was described as “medical equipment” implying a medical model rather than a community model. Many changes have occurred within this government branch since the early 1990's. Before this time, more equipment was available on loan. At the time of the interviews, the following assistive technology items related to this study were available: commode chairs, hospital beds, side rails, overhead bars, Hoyer Lifts.

Prior to the 1990's, bath stools, raised toilet seats, canes, crutches, walkers, and grab bars were also provided. The type of equipment provided by this program has lessened with government cutbacks. The Branch also bulk purchases standard and motorized wheelchairs which are distributed, maintained and controlled by the Society for Manitobans with Disabilities Inc. through Wheelchair Services.

Wheelchair Services

There are two programs operating under Wheelchair Services: the Standard

1. This and following references are from a four-page document from the Home Care Branch entitled "Program Objectives or Goals" which is not dated. See Appendix K-1.

Wheelchair and the Motorized Wheelchair programs.

Standard Wheelchair Program

Program documentation describes this service in the following statement:

“the Society for Manitobans with Disabilities Inc. act as service agents for the Province. Wheelchairs are provided to residents of Manitoba on a loan basis under physician's prescription.”²

Motorized Wheelchair Program

The second program is described in the same document:

“This program provides a limited number of motorized wheelchairs (approximately 30 per annum) to Manitoba residents who through an assessment process are deemed to be in need of a power chair. The assessment is performed by a Wheelchair committee who prioritize distribution by considering the extent of disability and whether the applicant is working or attending an educational facility. After approval the power chairs are purchased by [the Home Care Branch] and distributed by the Society for Manitobans with Disabilities Inc....

...This program is geared towards assisting the physically disabled who are employed or attending an educational facility. prioritization is required due to a limited number of power chairs available for loan.”

In order to qualify for a wheelchair, the individual must have a physician's prescription, illustrating the medical model in place. Prioritization is also given on the basis of extent of disability, vocational and educational needs. The Society for Manitobans with Disabilities also sells mobility aids and accessories including wheelchairs, scooters, canes, crutches, walkers, seating and home-care products. This has created some tension between the vendor and disability

2. Information quoted in this section is taken from either the previously mentioned document provided by the Home Care Branch or a pamphlet from the Society for Manitobans with Disabilities entitled "Wheelchair Services".

communities, both of whom feel that the Society for Manitobans with Disabilities has an unfair purchasing advantage over other vendors and can thus undercut their markets (Personal communication with investigator Feb, 1995).

Special Devices Program at Rehabilitation Engineering

The Rehabilitation Engineering Department of the Health Sciences Centre in Winnipeg provides prosthetic, orthotic, and special devices services for the "physically challenged".

According to their pamphlet, "*adults with disabilities have come to rely on the Special Devices Section for specialized mechanical and electronic aids. These aids include automotive adaptations, wheelchair modifications, and seating, communication aids, environmental controls, and many other aids to enhance daily living. Each device is custom made or modified to meet the client's individual needs*" (Departmental pamphlet).

To obtain these services, the individual can either contact the program directly or go through agencies such as the Canadian Paraplegic Association, Community Therapy Services, or various community interest groups. Multidisciplinary clinics are available when necessary for assessment of technology needs. This service is hospital based and uses the medical model of service delivery.

Occupational and Physical Therapy Assessments

Other than the Rehabilitation Engineering assessments, occupational and physical therapy adult assistive technology assessments are available through Community Therapy Services and occupational therapy services at many of the hospitals and long-term care

facilities. Occupational therapy services are also available at Ten Ten Sinclair. In most cases, assistive technology consultation is performed by occupational therapists. Expertise plus the amount and type of services available varies in these various organizations. There is one known private assistive technology consultation service operated by an occupational therapist and a rehabilitation engineer. These services are not funded by the government-sponsored program but are mentioned here for completeness. The number of private occupational and physical therapy organizations in Winnipeg is increasing and many of these organizations may offer some assistive technology consultations.

Formal Peer Counsellors

Although not formally recognized as part of the assistive technology team, formal peer counsellors were a very important team component mentioned by study participants. Formal peer counselling is recognized as that advice and assistance given by peers who are comparably disabled and who are paid by disability associations to provide advice and assistance. This service is available at Ten Ten Sinclair, Canadian Paraplegic Association and the Independent Living Resource Centre.

Idealized descriptions and flow charts have been developed by the investigator to characterize the four methods of assistive technology acquisition. To illustrate the usual process an individual goes through to obtain equipment in the government-sponsored programs, the flow diagram (Figure 8) on page 72 has been constructed by the researcher based on the data obtained.

Someone relying on the provincial government program either knows what equipment they need or want. If they don't know what they need or want, a primary source of information appears to be their peers. (This will be discussed later in Chapter 7: "Strategies"). The individual must then gain entry into the program according to certain eligibility criteria. Eligibility criteria for either the Home Care Equipment or Wheelchair Services is as follows:

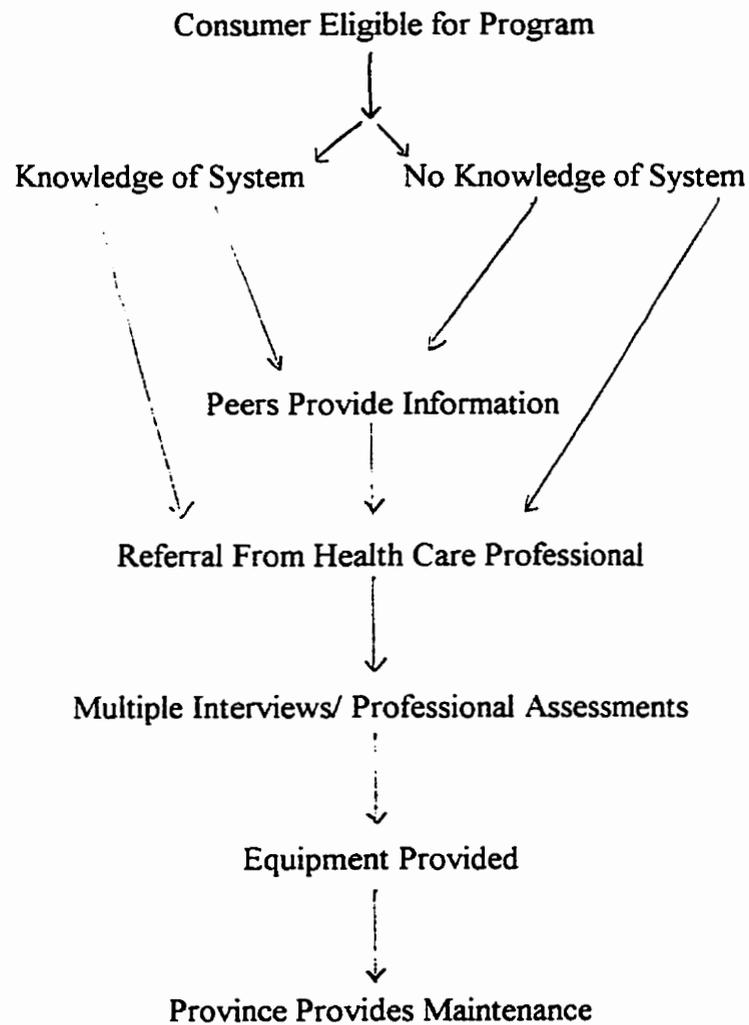
Clients receiving equipment from the Home Care Equipment Branch must be residents of the Province of Manitoba, must be registered with the Manitoba Health Services Commission and under the medical care of a physician, public health nurse or Victorian Order of Nursing. The medical condition of the client must warrant that home care is the most appropriate type of care. All requests for the loan of medical equipment must be placed by authorized medical personnel. Equipment is supplied to the patient without charge under the direction of a physician or other health care personnel. It should be noted, the program is a community based program and services are not provided to residents of health care institutions ie, personal care homes.³

³Information quoted in this section is taken from either the previously mentioned document provided by the Home Care Branch or a pamphlet from the Society for Manitobans with Disabilities entitled "Wheelchair Services".

Figure 8

HOW EQUIPMENT IS OBTAINED

Acquisition Route 1: Provincial Government Sponsored Program



As the previous paragraph indicates, the eligibility criteria is based on a “medical model” in which a professional determines eligibility. It specifies that the individual must be under “medical care”, equipment is called “medical equipment” and requests must be placed by “authorized medical personnel”. Equipment is under the “direction of a physician or other health care personnel. Although initially referred to as “clients” in this paragraph, individuals are later referred to as “patients”.

According to the Society for Manitobans Wheelchair Services pamphlet, other eligibility requirements include “Aboriginal persons with Treaty status through an agreement with Health and Welfare Canada”. However, “Individuals covered by Workers Compensation and the Department of Veterans Affairs as well as residents of personal care homes and institutions are NOT ELIGIBLE for loan, maintenance or service”

Individuals, who live in personal care homes and institutions, must pay for their own equipment. This, in effect, sets up an inequitable situation. Although not described in the materials available from the Home Care Branch, a professional assessment by an occupational therapist, a physiotherapist, or sometimes a nurse or physician is usually required prior to obtaining the equipment. In some cases, this step was circumvented, as described by individuals interviewed who “knew the right connections” or “who were known a long time by the system”. However, this did not always work as several persons with long-time disabilities described how they had to be assessed for what they felt were very minor types of equipment.

Equipment is provided from the stock available from Home Care, Wheelchair

Services or from Rehabilitation Engineering. Maintenance is provided by these services.

Acquisition Route 2: Insurance Coverage

There are several private insurance companies that cover the cost of assistive technologies, however, it is beyond the scope of this study to describe the policies of these various companies. As well, there are several public insurance companies that cover the expenses of assistive technology. These include Workers Compensation, Vocational Rehabilitation for Disabled People (VRDP), and Manitoba Public Insurance Corporation. (Indian Affairs and Veterans Affairs, Departments of the Federal Government, also cover certain individuals but these two groups are not part of this study.) Both the private and public insurance companies will occasionally employ occupational therapists on contracts from privately and publicly funded organizations to assess what equipment is needed.

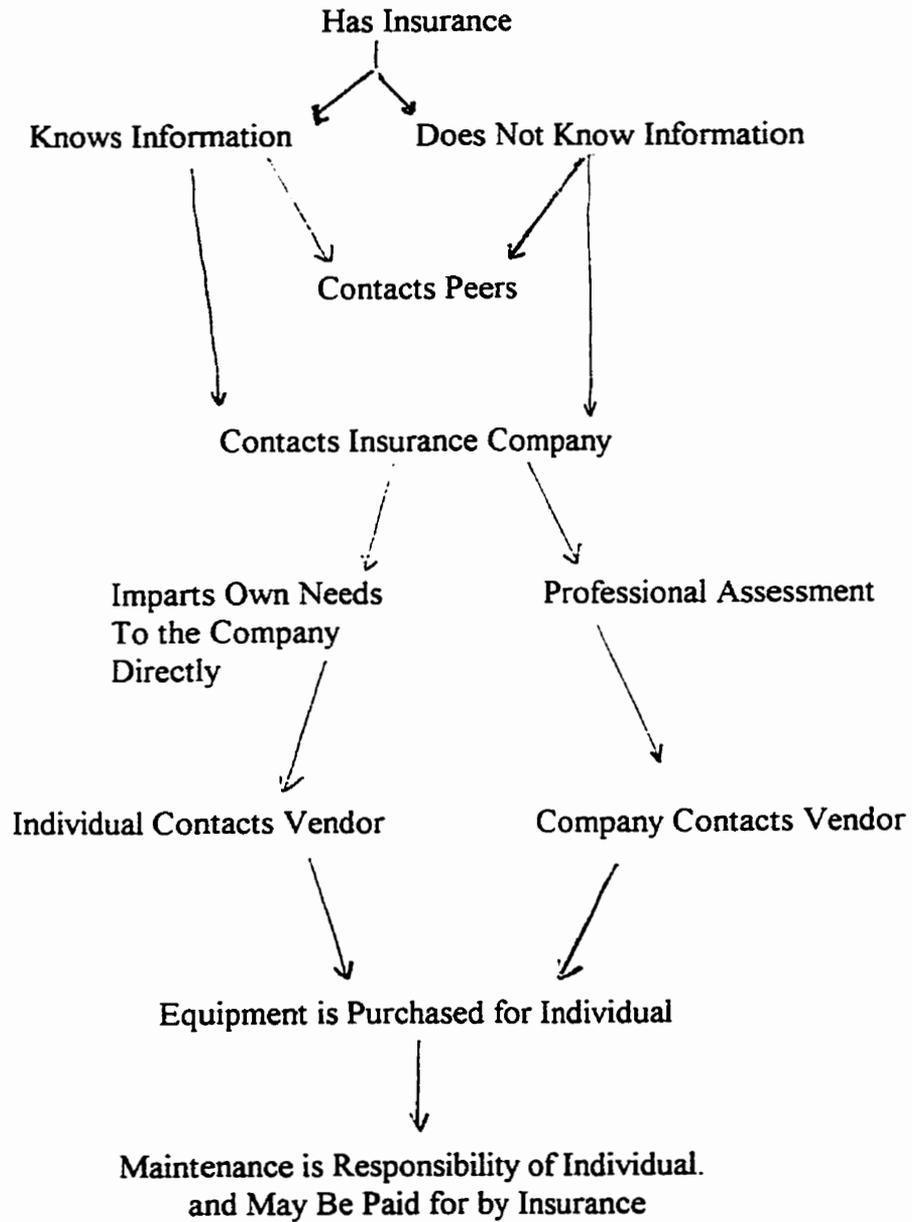
To illustrate the process of “acquisition of equipment” in this case, a flow diagram (Figure 9) on page 75 has been constructed by the researcher based on the data obtained.

Again the individual either knows what they want or need or they don't know and they seek the advice of peers. The insurance company may request a professional assessment by an occupational therapist, physiotherapist, or physician. For those who do not know what they want or need, this provides necessary assistance. For those who do know what they want, this may be considered to be just an added step. In some cases the insurance company will contact the vendors, while in other cases, the individual will contact the vendor directly. Maintenance may be the responsibility of either the individual or the company depending upon the specific terms of the policy.

Figure 9

HOW EQUIPMENT IS OBTAINED

Acquisition Route Two: Insurance Companies



Acquisition Route 3: Purchases Directly From Vendor

There are a growing number of assistive technology vendors in Winnipeg. Thirty-two vendors were found in the City of Winnipeg Yellow Pages (1994) who sold products used by individuals in this study. They were listed under various categories: Medical Supplies (17); Wheel chairs (6); and Wheel Chair Lifts and Ramps (9). Several of these vendors have formed a vendor association (personal communication Nov, 1994). It should be noted that some products for persons with disabilities are purchased from vendors who are not listed as providing “disability” related technology. Therefore, they would not be considered in this list. For instance, a 16" high toilet can be purchased from a plumbing distributor. As another example, some people get their power wheelchairs upholstered by an upholsterer (Based on results of interviews).

For professional assessments, a person can contact a privately or publicly funded occupational therapist for advice about what to purchase from a vendor after obtaining a physician's assessment. The person may then take his/her purchase to Rehabilitation Engineering Services for modifications.

The process that the individual experiences to obtain equipment directly from the vendor is illustrated in Figure 10, page 78.

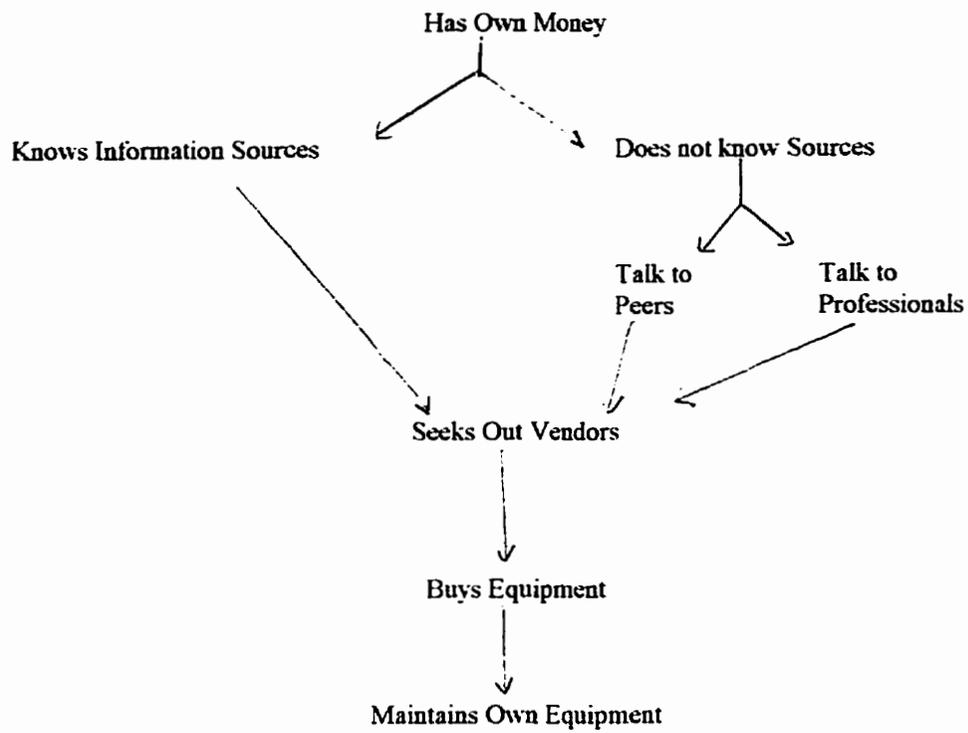
Again if individuals do not know what they need, they may talk to peers; they may also talk with professionals. They must seek out vendors, shop around for the price and the features that they want and then purchase the equipment. These steps are similar to purchasing other commodities in society. In this case, the individuals are responsible for

maintaining their own equipment and thus must seek out repair services. Note that one major difference between this “system” and the other two, is the lack of bureaucratic steps involved.

Figure 10

HOW EQUIPMENT IS OBTAINED

Acquisition Route Three: Purchases Directly From the Vendor



Acquisition Route 4: Mixture of Acquisition Systems

The majority of the study informants fit into this fourth category. They may use the government-sponsored system but they also purchase equipment directly on their own. Alternatively, they may receive some sort of insurance but use the government-sponsored system and also pay for some items on their own.

Acquisition Summary

The limitations and assets of the first three acquisition methods are outlined in Table 3, page 80. For instance, although the government sponsored method is free, respondents identified barriers including bureaucratic “red tape”, multiple professional assessments and limited choices available. Some equipment is dependent on whether or not the person works or is enrolled in an educational program.

Having insurance to purchase equipment means that the person would have to have had a traumatic injury resulting in disability. They still generally have to go through the bureaucracy, including professional assessments. Eligibility for assistive technology may be dependent on whether the item is deemed to be medically or vocationally necessary. Eligibility is also dependent on the type of disability.

When consumers have their own money to purchase assistive technology, they can deal directly with a vendor, potentially hire an occupational therapist and, as a result, have more control over the process. Acquisition method four has the advantages and disadvantages of all three methods.

Table 3

Critique of Each Assistive Technology Acquisition Method

	Limitations	Assets
Provincial Government	<ul style="list-style-type: none">- no choice- must go through professional- must go through red tape- lack of control- minimal equipment available- no direct contact with vendor- dependent on government definitions of work/education for some items- medical model	<ul style="list-style-type: none">- equipment is free- maintenance is provided- professional consultation is free
Insurance	<ul style="list-style-type: none">- some restrictions on what is covered, dependent on definition of disability- sometimes need a professional assessment to obtain- barred from many provincial programs if on insurance	<ul style="list-style-type: none">- more choices- may have direct contact with vendor- can usually get more equipment- maintenance usually covered
Own Money to Purchase	<ul style="list-style-type: none">- costs- must pay for own maintenance- limited supply of private professionals available for consultation- must get into government sponsored system to get free consultation from professional	<ul style="list-style-type: none">- direct contact with vendor- control over what is purchased- less waiting time

Context Conclusion

This section of the chapter began with a social-political perspective briefly describing assistive technology service delivery in Canada and the United States. Four assistive technology acquisition methods have been described to provide a backdrop or "context" to the core category of "acquisition of assistive technology needed for independence". The dimensional range described is one going from "little choice, little control, no cost" in the government-sponsored program to "having choice and control but costing a great deal of money" in the third method where consumers purchase assistive technology and equipment with their own money. There is also variety in the application of the medical model, dependent on the acquisition route used.

Chapter Five Summary

This chapter has dealt with the analysis of the data related to three categories of the Strauss and Corbin Model (1990) : the core category (acquisition of assistive technology needed for independence), the conditions and the context. The following chapters have been organized around the rest of the Strauss and Corbin categories of intervening conditions, strategies (actions/interventions), and finally consequences.

CHAPTER 6 - RESULTS : INTERVENING CONDITIONS

Strauss and Corbin's (1990) **Paradigm Model** defines intervening conditions as the structural conditions bearing on action/interactional strategies that pertain to a phenomenon. They facilitate or constrain the strategies taken within a specific context. (p.96)

In this case, the researcher has defined this category as those conditions which facilitate or constrain the **acquisition of assistive technology needed for independence**. These conditions or themes were chosen for this category based on interpretation of the data from the informants. Several intervening conditions were identified, including information sources, bureaucracies, choice, professionals, vendors, and accessibility of the built environment.

It is this researcher's contention that these intervening conditions are all examples of environmental factors which either facilitate or constrain the individual's ability to get assistive technology. The ability to procure assistive technology facilitates independence. The reverse is also true: the inability to procure assistive technology creates a barrier and constrains independence.

Disabled Peoples International (1981) defined handicap as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers". Social attitudes, policies and inaccessible environments, which disallow the acquisition of assistive technology create a handicapping situation for individuals with disabilities in which they cannot fully participate on an equal level with others in their community.

One frame work that recognizes the importance of the environment creating barriers or facilitators for persons with disabilities is that developed by Whiteneck & Fougeyrollas (1996). This researcher decided to frame part of the analysis using the model as was discussed in Chapter three. By framing the analysis within the Individual and Environmental Determinants of Handicap Situations and Social Participation Model (Whiteneck & Fougeyrollas, 1996), the researcher was better able to classify and justify assignment of themes to the Intervening Conditions category. This integration and analysis will be discussed at the end of the chapter.

The intervening conditions identified from the data analysis were:

- 1) information sources, 2) cost and eligibility, 3) bureaucracies, 4) choice,
- 5)professionals, 6) vendors, and 7) accessibility of the built environment.

Information Sources

Respondents described several possible sources of assistive technology information. These included disability-related magazines, therapists, peers, advertising from vendors, disability organizations, direct contact with vendors, vendor displays, ProductAbility¹ and ARCOR². However, most of those responding in this area were classified as “IL” meaning that they probably had adequate access to information. Many

1. ProductAbility was created as a product information service. Originally located at ARCOR, it did offer some product displays. However, after ARCOR closed in 1995, ProductAbility moved to Ten-Ten Sinclair. In 1996 ProductAbility lost a great deal of its funding.

2. ARCOR stood for the Aging and Rehabilitation Product Development Centre, a federally funded organization. The organization closed in 1995 after five years. ARCOR still existed during the time that interviews were conducted.

of these persons worked at disability organizations which directly provided this type of information to the public. It is important to note that not all “IL” classified individuals felt connected to information sources. Two persons who provided data in this area were classified as “NIL”. One of these people commented that she did not “have a clue” as to how to find out information on equipment. Even with this number of information sources several problems were identified, even by those classified as “IL”.

Problems with Information Sources

Five themes emerged related to problems with information sources:

- A) Three groups particularly seem to lack information
- B) Transportation to many of the vendors is difficult
- C) There is no place to go to check out products
- D) Information provided in magazine ads is haphazard; people seem to like to call peers for the information
- E) People do not know where to go to get information

Three Groups Particularly Seem to Lack Information.

The data indicate that three groups particularly seem to lack information: seniors with disabilities (007.IL 003.IL); the newly disabled (002.IL); and anyone who does not have a spinal cord injury (016.IL). The following passage implies that those who are not connected via professionals are on their own in the system and also implies variation in

how people qualify for this “information connecting system”.

Where do you get a wheelchair? How do you get a wheelchair? What kind of information? There are basically people who don't go into the Rehab hospital... They might end up being disabled because they're elderly and they don't need any social worker, they don't get any professional, they just need a wheelchair and in that area I found a fair amount of people saying that it's very complicated, you don't know where to get the information. Very often they phone the Red Cross. Well the Red Cross lends out certain kinds of wheelchairs but they don't sell any wheelchairs, so then you start looking around and some people have paid an astronomical amount because they don't know what kind of wheelchair they should be getting (007.IL p.7).

I've seen younger inexperienced users come out really having no idea even where to start on what kind of a product or even devices that are available... Some people, believe it or not, don't even know that a TOSC unit [environmental control unit] exists and just knowing you can really get a device that will turn lights on or off and open your door and that for you... And of course when it comes down to it, you do need some kind of access to the information or access to people who have that information or deliver that kind of information (002.IL p7).

This latter statement was made by an individual who works for a disability organization and whose job it is to advise on assistive technology equipment.

Several questions arise from these data. How long does it take for a newly disabled person to find information on assistive technology? What political and societal values influence the lack of access by elderly disabled people who receive less information than other people with disabilities such as those with spinal cord injuries? Why do persons with spinal cord injuries get more information on technology than persons with other diagnoses, such as brain injuries, multiple sclerosis, cerebral palsy, and spina bifida? Is it because they could potentially use more technology or is it because of greater advocacy activity among the members of this group? These questions need further study.

Transportation to Many of the Vendors is Difficult

In Winnipeg many of the assistive technology vendors are located in industrial parks, rather than in malls. This forces the individual to make a specific trip to the vendor location. One individual (014.NIL) discussed the difficulties with wheelchair transportation systems which would be used to get to a vendor. If HandiTransit is used, it must be booked three days in advance. Priority is given to those who work, go to school or who require transportation to go to a doctor's appointment. Although this individual is eligible for some private transportation, only 24 social trips are allowed per year, which is how a trip to the vendor would be classified. Therefore, the individual must protect those outing times.

There is No Place to go to Check Out Products

Several informants commented on the absence of a centre where a wide range of aids and adaptations could be evaluated:

I guess I've always wondered why we couldn't go somewhere and see what was available and have a little more choice and more information about alternatives and choice about what we were going to try. It's hard to deal in the abstract to decide what one needs.... I wonder what other things I don't know about that could make my life a lot easier, could make my life more independent, that if I had some better access to the information that I might choose to try and might ultimately benefit from (012.IL p5).

I'm not aware of a place that you can go to and check out, kind of thing and play around, without the bureaucracy there, without the professionals there, just some place where you can go and just look and see what's there (005.IL p6).

Information Provided in Magazine Ads is Haphazard; People Seem to Like to Call Peers for the Information

Informants also commented on the value of peer advice and hazards of advertising materials:

I think all people have access to that information because there are libraries, there are all kinds of magazines on the market that you can subscribe to if you want to. I find that a lot of people don't bother, it's a lot easier phoning up someone like myself or one of the counselors at the Rehab, or at CPA [Canadian Paraplegic Association] or phoning up the occupational therapy department or something like that and saying I need something like this rather than looking for yourself (016.NIL p5-6).

One possible reason for people calling up individuals for information, is that the information provided in magazines is provided in a haphazard fashion, usually only through advertisements. Some of these magazines are published in the United States and others are published in Canada. Most contain very little local advertising. Although the individual quoted above discussed how people do not bother looking things up, he also comments that products seen in magazines do not always do what they are supposed to do. There is such a variety of products, that it is difficult to say that one product is better than another without a complete assessment (016.IL).

Several questions arise from these data. How many persons with disabilities have access to or are actually subscribing to magazines containing information on assistive technology? How do people find out about “experts”? How long does it take after disability is diagnosed before the individual establishes contact with a disability-related association? Which diagnostic groupings and which age groups are most likely to call an association? Again further study is required in this area.

People Do Not Know Where to Go to Get Information

Two individuals (014.NIL, 012.IL) emphasized the problem that people do not know where to get information. One of these individuals, classified as “IL” who might have been expected to know where to access technology, in fact possessed minimal information. However, this individual was not working in a setting where he would come into contact with this kind of information. ProductAbility was a phone-in information source on assistive technology, yet when the name was brought up during the interviews, many of the respondents had never heard of it. Therefore, it would seem that the information is not being accessed and is not widely known within the disability community. One individual mentioned that he did not know what was available from Home Care (012.IL).

In summary, the problems of gaining access to appropriate information are best summed up by a respondent who stated, *"I think there is a lack of information, a lack of good information, and a lack of accessible information."* (007.IL p7)

Why is Information Necessary?

These data suggest that information is necessary to ensure that an individual with a disability

- a) gets a better selection of assistive technology (002.IL)
- b) is not at the mercy of the salespeople (002.IL)
- c) can make an informed choice (003.IL) and

d) can improve the quality of your life by knowing what is out there (002.IL).

It would also seem to follow that information can provide control over one's situation, in keeping with the principles of the Independent Living Movement.

Solutions and Recommendations from Respondents Regarding Information

The respondents suggested solutions to resolve this lack of information:

a) providing easy access to information was the main solution, including newspaper articles (003.IL); b) locating vendors in malls (005.IL) (014.NIL); and c) selling products in regular department stores and through regular catalogues (003.IL). This latter solution was to emphasize that assistive technology products do not have to be sold solely through medical suppliers; they could become everyday devices to be purchased at stores like Eatons (003.IL). One of the most frequently made recommendations was d) development of an assistive technology "display centre" where consumers could go to see items and try them out. Peers would work at such a centre. Some felt that this centre should include items available from the Home Care program. One individual stated:

In my mind it's sort of like a storefront sort of display area where those things that government decides to make available to people who need to maintain their independence are kind of shown together with some documentation, photographs or otherwise of how they're used, and I'm not saying there shouldn't be controls to make sure that people don't just take a little of everything and not use most of it...but there should be some sort of easier access to information on what is available. Perhaps the underlying problem is there should be more available (012.IL p 6).

Another recommended:

There is a need for being sensitive and learning how to communicate the potentials of technical devices for people including seniors who find these daunting so I think that's why the concept of a display centre hands-on full experiential open-access display centre is crucial so that people get hands-on experience and they'll take home a product to try out before they have to purchase it or get it from a government agency (003.II. p9).

These statements imply that the “display centre” would not be controlled by one vendor and that a variety of vendors and manufacturers could display their products. Vendors may argue that consumers already have the option of visiting their showrooms but one younger woman described her experience with this approach:

I've been to [Vendor] just because it's close to where I live. I went over there one afternoon and looked around but that one has just more wheelchairs and seniors stuff, which I guess one day I'll be but - - They didn't seem to have a lot of the kitchen stuff or other things (005.II. p6).

Vendors may tend to specialize in one area, therefore it was necessary to have a display centre containing a broader range of assistive technology.

A data base is required to know where to get specific technology and there should be a method of comparative evaluation of similar products. At the present time, the database and evaluation method is in the head of whatever expert is contacted and is based on experience since very little product comparison research has been done in the assistive technology field. However, respondents suggested that this information is very valuable and saves them hours of research. If these “experts” are peers it may add credibility to the advice provided.

This researcher also feels that the Internet promises to become a valuable source of product information to persons with disabilities. There are some vendors who have already established home pages; this will expand in the future. The computer offers persons with disabilities access to information without the barriers associated with transportation systems. However, it does not offer the necessary reality of seeing the product and having hands-on experience.

Conclusion: Information

In conclusion, there does seem to be a lack of information about assistive technology in the Winnipeg community. Lack of information results in the lack of informed choice for the consumer. Consumers' proposed solutions involve the provision of more accessible information which is not provided in a professionally/medically dominated manner. This perspective can be summarized in the following quote

So I think informed choice with tons of information and options and place to practice with the device before you buy a toaster or a T.V. or anything you need to be able to assess it and compare it with peers and see which products work- - one is a self-building process and one is a reliance on the profession doing it for you or a combination of the two. My best advice is that the relation with the professions needs to be one of consultant and we need to find a mechanism so it can be as healthy and constructive as possible (003.IL p9).

Although not explored in this research, the researcher's own experience suggests that professionals and vendors also feel there is a lack of information. They also have difficulty knowing what products are available. Perhaps by considering the solutions proposed by consumers and by making products and product information more readily accessible, all

stakeholders would benefit.

Inequality of Distribution: Cost and Eligibility for Assistive Technology

One of the main problems in having a disability and needing assistive technology is the cost. The costs of the vast majority of assistive technology are not covered by government programs. This means that additional items have to be obtained through other means. Assistive technology is seen by the respondents as having inflated pricing compared to items in the rest of society. (014.NIL, 017.NIL) Those who work and do not have any sort of insurance coverage must purchase their own equipment (usually because they have a disability originating at birth or with chronic disease). They benefit very little from income tax benefits.(005.IL) Some people are forced to access charitable funds raised by service clubs to obtain more expensive items. However, some individuals consider this process to be degrading (001.IL). All people interviewed appreciated the government-funded program even for the small amount that it does cover:

But then I'm also grateful for the wheelchair program. I imagine sometimes that if I didn't have the support of Wheelchair Services that I wouldn't have the ability to function at the level I'm functioning. I'd have a harder time, if I had to pay for all the equipment and servicing and everything else out of my pocket, my standard of living would be substantially lower - I can tell that because I have other things [like] prescription drugs, a lot of them are not available that used to be available. So I'm grateful for the system Manitoba has (0017.nil p.9).

Eligibility Requirements

For those individuals who qualify, some technology is covered by private or public insurance (Manitoba Public Insurance Corporation, Worker's Compensation Board), and

special government programs for employment training programs such as Vocational Rehabilitation for Disabled People (VRDP). Those on social assistance do receive supplementary coverage in addition to the universal program benefits which are provided. Eligibility for the amount and type of assistive technology available to individuals is dependent on variables such as: a) type and cause of disability and b) determination of medical and vocational need.

Type and Cause of Disability

If an individual is born with a disability, acquires a disability through disease, or in some cases, incurs an accident away from work, he/she has virtually no extra coverage for equipment needs. This is in contrast to someone who acquires a disability as a result of an industrial or motor vehicle accident where most of the costs are covered by the insurance provider. People on social assistance do get more equipment covered; however, it is usually dependent on assessment of “medical need”. It has been suggested that persons cannot afford to get off of social assistance and take jobs offering low wages because their equipment needs cannot be met if they have to pay for them out of their own pockets (004.IL). Those who have acquired their disability through trauma are perceived as being entitled to substantially more insurance compensation to purchase equipment and more tax breaks than others with disabilities (005.IL) .

The following example illustrates how equipment provision from an agency is dependent on disability type. This informant’s narrative highlights the difference in entitlement between a person with a speech impairment and a person who is deaf. The individual cited is a person who works at a disability agency.

The biggest problem that I hear about in my job is the issue of money: the cost of things that aren't covered by government programs. For example I recently had an issue arise where somebody who is speech impaired, who cannot talk, had wanted to try to obtain a telephone device for the deaf [TTY] so you see to talk on the phone to people using a telephone device. She can hear fine, her mind is fine but she just can't talk any more. Her speech is gone, and that's the difference she can't use the phone . Now the deaf community has a way of getting TTY's reimbursed through Manitoba Health. And if speech-impaired people try to go through the same program, they are told, "this is not for speech-impaired people, it's for deaf people". It's the same problem really and if she was deaf too then she could get it, but she's only speech impaired so they wouldn't help her with the money for it. That's an example of a financial kind of an issue , TTY's are 3 or 4 hundred dollars to get a decent one I guess maybe it's too much for her...she doesn't feel she is able to pay for it (004.IL p10).

Another respondent described a friend who is ambulatory using a walker. Because of this, she does not qualify for a “disabled apartment” or for some of the services others would get.

The suite that she's living in now she's lived for two months without any light bulbs in two of her rooms because the manager doesn't have to help a handicapped person put light bulbs in (011.NIL. p13).

Not only is money allocated based on disability type, it is also based on classifications of medical and vocational need.

Classification of Need: “Medical Need” and “Vocational Need”

As was described in Chapter 4, the Home Care program describes assistive technology as “medical equipment”. The Wheelchair program prioritizes allocation of power chairs to use by persons who are working or who are taking training. Even for

those who have insurance coverage, decisions about which equipment will be covered is often determined by assessment of “medical need”. The problem with this classification as the basis for compensation is in the definition of medical need. For instance, is the need for an elevator a medical need or a vocational need? If one has insurance that looks at “vocational need”, then one may qualify for the elevator since it could be argued that the individual needs the elevator to get out of the house to go to work every morning. However, an elevator would never be considered a medical need.

There do not seem to be clear guidelines about what is considered to be a medical or a vocational expense. The individual in the following example works as a consumer advisor with special expertise in benefit determination and even he did not have a clear idea of what needs are covered. He explained about some of the items in his home that were covered by Worker's Compensation.

Interviewer: Yet they wouldn't pay for the intercom?

R. Ya, that's where I get lost, when I asked them what the rationale is they'll tell me it isn't a vocational expense or it isn't a medical expense or something like that, and -

Interviewer: But they paid for the elevator.

R. Ya, I guess it allows me to get out of the house so I can get to work, I suppose you could argue that. I'm not sure how that all works and I suppose the vocational counselors and I'm not sure what all the titles of the various people who work at the Worker's Comp are but I guess they have a set of guidelines that they follow and I suppose some of them follow them to the letter and others sort of advocate to their supervisors on the client's behalf, I'm not sure how that really works (O16.IL p.5)

Because people have argued with insurance companies and Revenue Canada, these

organizations have now somewhat expanded what they will classify as a “medical expense”. For instance according to respondent 016.IL, Revenue Canada will now consider a van lift and some home modifications as “medical expenses”.

This researcher argues that there does not seem to be a category entitling consumers to compensation for the cost of “independent living needs” ie: needs that go beyond “medical” or “employment” categories. For instance, a computer with adapted hardware and software can enable the consumer to achieve productivity and leisure participation. However, one individual explained how social allowance would classify a computer or van:

I don't know all the rules of the social allowance program to be honest with you but I think that they look at things that are medically necessary and a van I don't think would be classified as being medically necessary. A cushion would be covered possibly but a van lift, I think would not be covered. I don't know - some devices like the computer for example might not be considered medically necessary and so they might not provide that.

Interviewer: It's almost like a medical system rather than them looking at it as helping you become independent.

Respondent: There's no equipment program right now that's an Independent Living philosophy. As far as I know it's all based on either a medical need or sometimes people seem to get the equipment through the VRDP program that will enable them to be employed and so they can use that kind of an argument. If you need special equipment for a job, often you can get it through VRDP, but if it's not related to either medical condition or an employment situation than there are no programs that I'm aware of that will help people with things to just help them live daily (004.IL p-5).

One individual discussed the lack of entitlement in areas not covered by vocational compensation as a human rights issue. He stated:

A lot of this is attached to employment, a lot of things are attached to how motivated people are, whether they're involved in the community or not. Those are the people who get top priority. If you happen to be just a quiet person, sit at home and watch T.V., read books and enjoy your balcony and maybe some flowers on the balcony, people watch and those kinds of things, you would not be a top priority for these special devices, which is unfortunate because they have as much right to that lifestyle and getting from the T.V. out on the balcony is as important for them as it is for me to get from here down to The Forks³ (009.IL p.9).

The data show that assistive technology entitlement is based on the medical model rather than considered as a human right. A few other authors have discussed this area of medical need and denial of assistive technology (O'Day & Corcoran 1994, and Donovan, Carter, and Wilkerson, 1987). Donovan et al (1987) received 110 responses to a questionnaire sent to members of the American Spinal Injury Association. They found that 180 pieces of equipment had been denied. One half of the items denied were eventually procured, indicating that perseverance may pay off. The majority of respondents relied on families or charity. The authors commented that the reasons given for denial revealed a shallow level of comprehension by some third party payers about the importance of "durable medical equipment".

Proposals from the Consumer Organizations to Address Cost and Eligibility Issues

Consumer groups across Canada have been invited to submit proposals to the Federal Social Policy Review which has taken place over the past two years. The Manitoba League of Persons With Disabilities (MLPD) and the Council of Canadians with

3. The Forks Markets is a historic site, federal park and a market place in downtown Winnipeg.

Disabilities (CCD) has put forth a proposal to assist consumers in recovering the extra costs associated with disability (CCD, 1996). They propose a better tax credit system. Assistive technologies are not specifically addressed in the CCD proposal but are implied. An informant summarized the proposal:

Well, we were very involved in the Federal Social Policy Review.. In there we are proposing a way to deal with the issue of cost through the tax system by making equipment that people need completely refundable through taxes. So if I buy a \$4,000 lift for my van I could put it on my taxes and get \$4,000 rebate and we're recommending that. That idea is being recommended by many organizations, not only ours...The proposal is that there has to be some gatekeeper for the money, because no government is going to accept self-determination, even though we might like to propose self-determination. We've recommended to the government to create some sort of process that involves users, consumers, disabled people and professionals and that system be mandated to have some authority to verify the needs for equipment (004.IL p13).

Critical to this discussion is the phrase "no government is going to accept self-determination". The assumption which might be made from this passage would be that self-determination would mean giving the money to the consumer who would then choose his/her own equipment. The consumer organizations have recommended a compromise involving various constituents in a process of gatekeeping.

This concept of using a gatekeeper would fit one informant's perception that some people who had comprehensive insurance coverage tended to use their benefits to acquire equipment which they did not need. He proposed that there should be some sort of regulation.

I know people who are covered by various insurances and they purchase all this stuff or they got themselves a big settlement and they've purchased all kinds of needless equipment and then it's basically rotting in their basement. There has to be some kind of a policing , for lack of a word,... without denying somebody something that they need, I don't know how you'd do that but I think I'd like to see that (016.II p20).

Conclusion: Cost & Eligibility

In conclusion, cost is a very important factor in determining one's ability to acquire assistive technology. Although some people qualify for insurance or government programs that allow for more of the equipment, these programs are dependent on meeting the criteria of specific classifications of disability and on medical and/or vocational need. There are no programs that consider "independent living needs" in Manitoba. This means that if a person requires a piece of equipment to be independent, but which is not required for medical or for vocational need, it will not be covered. Individuals who have a non-traumatic disability and who work were perceived as receiving the least benefits. Consumer organizations have put forth recommendations for changing regulations defining entitlement to benefits to the Federal Social Policy Review. Although consumers would like to have a system which maximizes self-determination, they realize that the government is unlikely to agree to this model and have offered a compromise in the form of a panel of gatekeepers. However creation of such a panel also potentially risks creating another level of bureaucracy. It seems that at this time there is a clear inequality in the distribution of assistive technology in Manitoba.

The Impact of Bureaucracy on Equipment Acquisition

One of the most frequent areas discussed by respondents was the “bureaucracy” that controlled assistive technology. (The term bureaucracy was defined by the respondents in the popular context rather than by a sociological definition). In referring to “bureaucracy” the respondents described the numbers of people they needed to contact and talk to, even when they required only a simple device or when they knew exactly what type of assistive technology they wanted. As will be illustrated in the following examples, bureaucratic barriers created time delays and instilled in consumers a feeling of not being trusted to know what they wanted. Generally, "bureaucracy" was seen as a significant barrier to obtaining assistive technology.

Themes highlighted in this section are:

- a) lack of coordination across multiple bureaucracies
- b) needless contacts by professionals
- c) bureaucracy creating time delays
- d) bureaucratic barriers because persons with disabilities were not believed
or thought to be incapable of making a decision
- e) consumers doing without rather than going through the bureaucracy.
- f) inflexibility created by bureaucracy

Lack of Coordination Across Multiple Bureaucracies

In the following example, the individual described the process of getting his van

modified by Rehabilitation Engineering and approved by the Motor Vehicle Branch. There appears to be a lack of coordination across the two bureaucracies which make competing demands. It should be noted that this was not the respondent's first adapted van. There seems to be a "Catch-22" situation created by the process of getting vehicle modifications made. This individual also pointed out that the process was intimidating to him. This acknowledgment was significant because this person a leader in the IL movement. He stated:

It's hard to find your way through the bureaucracy but it's not only Rehab Engineering's bureaucracy, it's also Motor Vehicles, licensing and so on. You have to get your vehicle equipped so that you can take driving lessons so that you can get a license - but to get your vehicle equipped, you're supposed to have a license - there are those kinds of dilemmas like inconsistencies, ironies where...it really seems insurmountable sometimes to know how to satisfy all the areas - bureaucracy - the demands of the various bureaucracies which are in conflict with one another. If you're starting where you've never driven before, you don't have a license and a record.but it's very intricate, very difficult, and very sort of intimidating as I recall (.012.IL p.9-10).

Needless Contacts by Professionals

In the following passage, the individual discussed the experience of acquiring low-tech assistive technology items in a process which required him to submit to multiple interviews with professionals. He described not only the cost in time away from work for him, but also implied that the cost to the system was unnecessary. In the first part of the passage he detailed interviews which included discussions about equipment and needs for attendant care.

I would sometimes have to stay home from work ... and they would go on it seemed for an hour and a half with two people answering alternatively two people questioning about a great variety of things. I thought it was a little bit onerous...At one point I had to have a bath board replaced because it was breaking or broken, because I had used it for a while, water damaged, or whatever and that wasn't very difficult actually but still it took a little bit of time, it took a few phone calls - I think it took another interview. I guess my general impression was that these devices I was using and that I had the benefit of through the program [Home Care] were fairly low cost and were fairly simple and the amount of resource investment in the process was primarily personnel and time. By the time two professionals came to see me two or three times for an hour and a half each, ... the cost of delivering the items was probably exceeded by almost ten fold by the process. It took also my resources and energy to accommodate that process, so I had a little criticism of the balance there. It seems to me it should have been an easier more streamlined way to have access to those low cost items (0012.IL p.5).

Bureaucracy Creates Time Delays to Acquire Equipment

In the following narrative, the respondent described that she had just moved into a Fokus Housing unit. She had seen a lift for the seat of her power chair which she felt would be handy to get to higher cupboards and to reach filing cabinets at her new job. To get the device, she again had to go through a process that took months.

And get him [the physician] to approve it saying, yes I need it, and then it had to go to Rehab Engineering and then they said okay and they finally put it in but it just took those extra months to push it all throughIt didn't take a couple of days, it took a couple of months to go through and Rehab Engineering, at that time, was the only place that was doing this kind of stuff, so they were really backed up with other equipment and things they were doing for other people. Waiting list kind of thing (.005.IL p4).

This delay created by the need for her to deal with multiple bureaucratic layers no doubt would have had some effect on her functioning in the home as well as at work.

Bureaucratic Barriers because People with Disabilities are not Believed or Are Thought
to be Incapable of Making a Decision

In the following two examples, the respondents expressed the feeling that assessments for equipment by professionals were made because persons with disabilities were not to be believed. These respondents were talking about very simple devices that, in some cases, they have had for years. One persons stated:

A therapist came out and said "ya I did need it" and then my doctor wrote a letter to social services that I needed it badly and then you go from there. It might take longer - month or so but in the long run you get it, I think.... I knew what I needed and I wanted it. Why do I have to go through all this rigmarole? Come on! Aren't I smart enough to tell you? - I mean - I need a lift in the bath tub - Please get me one. What more does a therapist know, how does she know what I need? She doesn't live in my body. ... I think that - a lot of things, never mind the bath tub lift, we had to have an occupational therapist or whatever to assess you - what for? Why not just say, " Hey guys I need this, I know I need this because I can't do it on my own, so please, I need this." I think they think we're all stupid (014.NIL p4).

Another commented:

Ya, because they didn't make the ones that I had and so they had to come and re-assess me. I guess that's the frustration for me is them not believing you - like I'm the consumer, this is what I need. I know my needs better than what you do, sort of thing (05.IL p5).

The idea of the consumer as expert with special knowledge of his/her own situation, expressed by the Independent Living philosophy, is eroded by the notion of the necessity of professional assessment. The philosophy of persons with disabilities being able to take risks and responsibility is also contrasted to a bureaucratic system which requires

professional assessments for every item.

Consumers Do Without Rather Than Going Through the Bureaucracy

Some respondents indicated that persons with disabilities do without equipment rather than going through the bureaucratic process. This process was described as “hell” by one individual .

It's just that you have to get an O.T. to come down and approve that you need this ... I'm saying I need it and you think I'm going to lie about this kind of thing? I don't have any connections with O.T.s and I haven't in years..... so I avoid I guess all of that other stuff. With my electric lift,[for her wheelchair] again I had to get a medical doctor to sign saying, 'Yes, she does need this lift' (005.IL p3).

Another respondent described an experience she had trying to purchase a product (Spenco) which she applied to her trunk to prevent pressure areas. She had always purchased the product on her own from an occupational therapy department. One day the policy changed and she needed an occupational therapist's assessment to obtain the item.

I've been using it for years, now you tell me because there's a new policy in place that I can't get it. So those kinds of things really annoy me. You can't take the word of a consumer - it's not even like I was doing drugs. If I was saying I really need another 200 Valium, I've been doing it for years so just give it to me, it's not even anything remotely close to that, it's a little piece of foam, and so - those kind of things I think are a waste of time and energy. It's very frustrating so people do without things. You don't want to go back if you go through so much hell, so those kinds of things I would change. I would say, you know if a consumer says it's what they need then I would say this is what they need. I think that there may be issues with different individuals who may have disabilities that affect their cognitive judgement and then you need to look at that, but I think you need to look at it as an individual. Look at these issues all individually and maybe it might take a little more time but I think then

you'll be fitting the bill of what you're supposed to be doing. That's how I'd change it. That's my idealistic world (.001.IL p. 10).

Her recommendation is that every situation be looked at individually. If an individual really knows what she wants, why spend all of the extra money on a professional assessment to end up with the same end product? Again she expressed the idea of not believing the "word of the consumer".

Inflexibility Created by Bureaucracy

The repair of assistive technologies, in particular wheelchairs, illustrates the inflexible nature of bureaucracy. When people discussed repair services, most of them were describing the repair service offered free of charge by the Wheelchair Program at the Society for Manitobans with Disabilities. Respondents were happy with the fact that the wheelchair program technicians would make home or office calls and would even meet the individual on the street; they found the technicians to be very helpful. (012.IL, 017.NIL, 014.NIL, 008.NIL). The main complaint directed at the program was the lack of provision of repair service after 5pm and on weekends and holidays. If a wheelchair needs to be repaired after business hours, the individual is forced to use a manual chair for this time period and this can severely limit the functioning of someone dependent on a power chair. This problem also occurs in situations in which it takes days to repair the chair. One respondent described that in these situations, he was forced to spend time in bed because this was the only way he could operate his environmental controls. He could not go to work. (008.NIL)

You don't have a back-up power chair - limited number of power chairs but especially in the rural areas or outside of Winnipeg, the back-up availability is extremely important because it may take days or longer to have a repair done on a chair, so you have to double your rolling stock by not having any kind of holiday or 24-hour repair capacity. The people in that program recognize the problem and have been trying for many years to achieve a funding base where they would be able to provide a crisis or weekend service. The solution of a back-up to a manual wheelchair user is quite effective but to a power wheelchair user, someone not able to really be mobile with a manual chair, when your power chair breaks down in the early part of a weekend, you're really immobile for the rest of the weekend until office hours open again, and that's a terrible cost personally. You have to rely on someone else to push you around. If you live alone, you have to have someone really come and stay with you and it's a serious problem in the program (012.IL p.8).

In the following excerpt, the respondent stated that he had even tried to hire a private repair service to assist in this situation, but they refused to service a wheelchair provided by the Society for Manitobans with Disabilities. The respondent thought this happened because in the past, the services have had bad experiences in getting paid. He described how, through his frustration, he initiated change in the system wherein the technicians now carry emergency pagers during weekdays.

So you break down at 5 o'clock, you break down on the weekend and you're in a lot of trouble. Even during the day, during business hours - there was a time I ended up with a wheel broken, I was lying in the gutter outside the building and go and call people and they say, "Well we're very sorry the technicians are in early in the morning, they take the calls that are set up for the day, they leave and they don't come back into the office", so if you break down at 9 o'clock in the morning, great, but if you break down at 10 o'clock in the morning you have to wait til the next day, At that time I wrote a very nasty letter to the Minister and said, I'm sorry that my chair doesn't observe office hours, So the response I got was

“well you know there's been proposals for having an emergency service in off hours and it was just too expensive. One thing that I'm hearing from what you're saying is that we will arrange for there to be more responsive during the day.” This is already a couple of years - one of the guys has a beeper, one of the technicians. If an emergency thing happens during the day, they can beep him and send him on an emergency call, that did happen...But you know it gets very frustrating. I have often had troubles in the evenings or on weekends... So far, thank God I've not had any really serious trouble. I've had to even call the police to get me off of the floor and then call courier service to bring my manual chair from my house in the north end so that I'd have something to get into and then arrange for a courier to take the broken chair to be serviced or at least to my home until I can arrange for them to come and service it. Those are some of the frustrations, the purpose of these programs is to keep us functioning and I don't function during 7 or 8 hours of the business day, I function around the clock, I only sleep 6 hours a night yet the systems are not there to provide support (017.NIL p5-6).

Although this study deals with urban residents only, for Manitobans living in rural areas, access to services appears to be much more of a problem. The following respondent, who was not from rural Manitoba, described his awareness of the problem gained through his broad connections with disability organizations around the province.

You sort of got to cope with trying to send the wheelchair into the city in some cases using freight truck or bus, or having a part sent down, a wheel or some other part that can be sent out, and local handyman maybe helping to do some emergency patch kind of stuff. They have clinics I think once or twice a year where trucks with technicians and parts move around to various centers in the province and people will go to those for a kind of regular maintenance or to repair small things that have been falling apart since the last time the truck was in Dauphin or wherever it is. It's probably the best you can do though in a provincially offered program given Manitoba's demographics - half the population or more in one centre and the rest scattered over thousands of miles (012.II p 9).

Future studies are needed to address the unique problems of accessing services

encountered by people living in rural areas.

The Results of the Bureaucratization of Assistive Technology on Service Delivery

The following passages point out several important areas which contrast with the Independent Living movement philosophy. The passages show that as a result of barriers in the bureaucracy a) the consumer is not allowed to make an independent decision; b) some professionals are inappropriate gatekeepers in regulatory access to assistive technology due to their lack of knowledge in this area; c) there is an assumption that all consumers with disabilities are attached to a medically-orientated system; d) the system related to assistive technology is inequitable compared with systems which allocate other commodities in society; and finally e) a power differential is created by the process of bureaucratization of assistive technology.

The following extended quote by one consumer is presented in terms of these five discrete themes related to the results of bureaucratization of assistive technology.

Reference for the passages is provided at the end of d).

The consumer is not allowed to make an independent decision.

I think that the biggest downfall of all of this would be the fact that consumers really still end up not being able to come right out and say, "this is what I need, this is what it should look like and this is where I want to get it"

Some professionals are inappropriate gatekeepers of assistive technology due to their lack of knowledge in this area.

You really don't have that flexibility, if you're looking at getting funding for it because you have to have a doctor say you need it. Now my doctor is a general practitioner and she wouldn't have a clue come hell or high water about technical aids that I would need, so if she would sign anything or do anything, she would be doing it simply on what I said. She would be the one approving it, and I take real offense to the fact that I can't specifically go to a service and say, "this is what I need". Even Blue Cross they probably want a doctor's certificate saying I needed scy a thoracic support. My doctor wouldn't know, I would tell her probably what to write in the letter, but because she has this medical degree it's considered as a valuable resource.

There is an assumption that all consumers with disabilities are attached to a medically-orientated system.

I could see them saying, even a therapist, but it's not like I have a relationship with a therapist on an ongoing basis. Because you're in a wheelchair it doesn't mean you are connected to medically related institutions and believe me those of us who can, stay away from them as much as possible. There's just a real annoyance for me to say that every time I need anything I have to get permission from a doctor who may not have a clue of what it is. It's not just with technical aids, it's the same if you want to get Handi-Transit. You have to get a medical certificate saying, yes, you do have a disability, and it's like, well, what the hell, so it's certain things that are still bad.

The system related to assistive technology is inequitable compared to systems which allocate other commodities in society.

It's not that I don't see there needs to be some kind of control mechanism but if an able bodied consumer can go out and buy a car, why shouldn't I be able to go out and buy a wheelchair, if the consumer is getting a loan for that, then I should be able to have the same right to get a loan. In that sense, from that end of it there's just certain - I don't know there's inequality (.001.IL p. 9 p450-478).

This respondent's statements in each of four thematic areas emphasizes the inequitable nature of the system providing assistive technologies. It confirms Hahn's (1984) minority perspective on disability- in this case that the process of acquiring assistive technology is

inequitable compared to the process of acquiring other commodities in society. It also confirms DeJong's (1979) perspective, the assumption that all people with disabilities are attached to a medical system. This respondent also felt that there should be some control mechanism or gatekeeper regulating access to assistive technologies. However he also emphasized that those purchasing assistive technology should enjoy the same rights and freedoms as consumers who acquire other commodities in society.

A power differential is created with the bureaucratization of assistive technology.

In the following two passages related to bureaucracy, there was an underlying theme of “power” - emphasizing the lack of power felt by the consumers. Respondents felt they were not believed; they felt they had no alternatives and little choice. Government-run programs can be considered monopolies since it is the only source of assistive technology for most people in the province. Professionalization of assistive technology creates gatekeepers who wield an incredible amount of power related to decisions affecting people’s lives.

*... They [Rehab Engineering] kind of have a monopoly on a lot of this stuff. For example, their arrangements with Motor Vehicle Licensing is that they install the hand controls or that they together with occupational therapy all have a role to play with Motor Vehicles. They're the only game in town in terms of diagnoses, prescription, technical aid installation or fabrication and then licensing, so you **don't have a sense of being a consumer with any kind of power**, because there are not alternatives. So its a closed shop.... Well, you also have to remember that they've got a waiting list - sometimes you have to wait months to get things that are very important to us - seating or other things, so there's not much sense of choice. You get what you need, what they will agree you need*

and what occupational therapy has, after their examination, indicated you need in order to be able to drive. There's not much real choice there, alternatives. I think there's a willingness to listen to ideas as to how to go about it and that's good. But, a lot of those questions have already been settled by occupational therapy (.012.II p. 10).

The message from this passage is that the program's "willingness to listen to ideas" is rather token.

Elaborating on the concept of a power differential, several of the respondents also spoke of being careful not to get the professionals' "noses out of joint" to avoid having problems getting their equipment. It should be noted that even though the following respondent is a well-connected consumer (classified as IL), he feels intimidated by the system.

I think I was probably a little intimidated, like I say the power to grant you these devices or to certify that you get a license is absolutely not your own - it's absolutely vested in the people and there is a system of trust and collegiality of the various actors.... it's a little network of people, and so they all are part of the gang. If you get somebody's nose out of joint you're not going to - doesn't improve your chances of getting that license. So if an O.T. tells me I need a cushion behind my back, I don't think I do, I wonder if it isn't dangerous but if she's strong enough on it I'll probably go along to try to move the process along and then throw it away later when I confirm in fact that it's a risky thing for me (.012.II p12).

Suggestions for Changing the "Bureaucratic" System

Some of the respondents stated that they would like a system for acquiring assistive technology similar to that provided by Rehabilitation Engineering wherein they could visit the engineers to discuss what they wanted without having all of the assessments and signatures. Although this more co-participatory procedure seemed to operate in this

way for some of the people, it did not in all cases. Some of the respondents felt there was a bureaucracy that they had to go through to access Rehabilitation Engineering.

There are probably many reasons for this requirement that the technology user complete a system of multiple interviews for even relatively simple technology. The following respondent suggested several possible reasons for this, including the protection of the consumer from risk and the belief that professionals know best and protect the taxpayer. Although agreeing that there should be some controls, he made suggestions for change which included: a) separating the assessors from the gatekeepers and b) allowing individuals to take risks and responsibility for their own actions. (This long passage has been divided into three sections to accentuate specific points. Reference for this passage has been placed after the third paragraph.) The informant stated:

There probably is the element of protecting the consumer from risk, there's also the belief that the system and the professionals know the best answers, and again protect the taxpayer dollars. I've always argued this with my good friends that there's no point in spending four times the dollar of a product on assessment in order to make sure that one quarter of it is spent wisely and even then it's a guess on which product is suitable.

Separate the assessors from the gatekeepers and provide informed choice.

He continued:

I think there's a whole question of providing consultation to consumers with folks that are objective, particularly professionals, without them being the same people who are gate control of people and saying you can or can't buy this equipment... There needs to be informed choice the society should provide informed choice to people, the best relationship would be professional consultation and options, but not through the same bureaucrats who control, limit the dollars and choices So it's a whole

gatekeepers system that's under review and needs to be examined...

Allow individuals to take risks and responsibility for their own actions.

He concluded:

There needs to be accountability, there also needs to be a transfer of risk and responsibility to individuals who make open choices and to bear the consequences of those, and that may fly in the opposition of do-good agencies and the professional status who may feel that in the training and their mandate that they're responsible for the right choice made and their adjustment as to what the right choice is. So I think there's still a diversion of opinion between who can make the final choice and who is the consultant and who is the decision maker, and that is what the Social Review is getting into right now (.003.IL p7).

The concepts discussed by this individual - the ability to take risks, to assume responsibility and to make informed choice are all basic to Independent Living principles.

Many respondents stated that there were times when a professional assessment was necessary such as in situations when individuals needed “highly specialized” items. Again, many respondents in these interviews suggested that a technical aids display centre should be set up to enable individuals to try out devices before acquiring them from any system (including both private and publicly funded systems). Such a centre would be a mechanism for achieving the previous individual’s suggestion of separating the assessors from the gatekeepers.

I think there should be a place to test out the equipment.... I think there is a need to make it more flexible and easier access by disabled people and disabled people make the kind of choices that they need to and have more control over the situation. I think it would cut out a lot of time that professionals spend on these things which I don't think is always necessary (.007.IL p 7).

Conclusion: The Impact of Bureaucracy

This section has highlighted bureaucracy as an intervening condition between the consumer and the assistive technology that he/she requires. Several themes were discussed in this section including the lack of coordination across multiple bureaucracies; needless contacts by professionals; the time delays created by bureaucracy; the bureaucratic barriers created by the attitude that persons with disabilities are not to be believed or are thought to be incapable of making a decision; consumers doing without rather going through the bureaucracy and the inflexibility created by bureaucracy.

In conclusion, bureaucracy is instrumental in the creation of a power differential between consumers with disabilities who are forced to accept the decisions and professionals who can be uninformed about assistive technology. The respondents suggested several ways of making bureaucracies more accessible and the process of acquisition of assistive technology more dependent on the individual consumer's requests and expertise, rather than on the "expert's" assessment. The respondents suggested that simplifying the process would save both time and money. A modified system would provide some controls over the acquisition of assistive technology which would eliminate waste and ensure that expert advice was available as it was needed.

Choice As A Barrier Or Facilitator To Accessing Assistive Technology

Although “choice” is one of the guiding principles of the Independent Living Movement, it appears that the current government-sponsored assistive technology system in Manitoba offers little in the way of choice. Most people who were interviewed (especially those involved in the IL movement) were not happy with the present lack of choice in the system. (002.IL, 003.IL, 004.IL, 005.IL, 009.IL, 010.IL, 012.IL, 015.NIL, and 016.IL). Respondents focused on three sub-themes regarding choice: a) the Society for Manitobans (SMD) Wheelchair program, b) the Home Care program and c) bureaucracy in general.

Choice in the Society for Manitobans with Disabilities Wheelchair Program

According to many of the respondents, the current situation, and one that has existed since the establishment of the Society for Manitobans Wheelchair Program, is that only one brand of wheelchair is provided - chairs manufactured by Everest and Jennings. Respondents explained that their understanding of the rationale behind this policy was that it would be difficult to stock parts for other types of wheelchairs which, in turn, would interfere with the repair service. As well, by dealing with only one company, the Society for Manitobans with Disabilities had access to lower prices (016.IL, 012.IL, 008.NIL). One informant commented on the monopoly situation:

Ya, Everest & Jennings sort of has us by the throat, but that's a system

that's - there are things that you don't have and maybe I understand why you don't have choices. They can't stock 5 or 6 different brands of wheelchairs, not 'cause they couldn't sell 5 or 6 different brands of wheelchairs, but couldn't afford to keep the replacement parts, and they're going to break down. So if you've got one brand of chair, E & J, you've got parts for a whole lot of chairs (008.NIL p.13).

According to some of the respondents, there have been attempts by consumers to lobby for change in the wheelchair program, but nothing has changed.

Ya, well that's what you hear over and over again and we've been after (we, the CPA) them and I'm sure others have to change the program for years and that is the common answer is that we have E & J chairs, we stock E & J parts and it would cost just too much money to change over... It seems from what I understand, it's a government contract and for some reason or other they just stick to that one program, whether that'll ever change I don't know (016.IL p.6-7).

In the following example, the choice of type of wheelchair (among the models manufactured by Everest and Jennings) was also limited. Access to specific types of chairs depended on the type of disability. The chair the respondent described is a lightweight wheelchair. The respondent also pointed out that many people with lower-level quadriplegia and paraplegia were experiencing shoulder problems which could be attributed to pushing a heavier weight wheelchair for several years.

The only changes I've seen in that program is they've gone from the "standard E & J Chair" to at one time there was E & J Sportsman that they would provide but only for spinal cord injured people and only if they were quadriplegics... because paraplegics were "strong" and had full use of their arms and they can wheel around an E & J chair with "no problem". My argument to that is if you follow that line of thinking and

everybody who doesn't have a physical disability should not have any of the conveniences such as a remote control or heaven forbid any kind of technology that makes life easier because physically you can do it so you don't need it. Why should a paraplegic or a higher functioning quadriplegic have to use something that is more difficult and more cumbersome and doesn't give them the independence that something better would do (016.IL p. 6-7).

So lack of choice for some people has resulted in an increased level of disability.

The interviews also revealed that the program was so effective at repairing and recycling the parts of wheelchairs that one individual can use the same chair for years (014.NIL). Although saving money, it limits choice since people cannot get newer models. They must live with twenty-year old technology.

Choice in the Home Care Equipment Pool

The range of assistive technology provided by the Home Care Equipment Pool has diminished in recent years due to government cutbacks. At the time of this study only a minimum number of types of assistive technology were provided. However, even for the equipment that was provided, respondents commented that there was only one type of selection available. One respondent stated that he thinks decisions made about the types of wheelchairs provided are based on economic considerations only and he perceives much of this equipment to be out of date. There is a sense from the interviews that Home Care is not keeping up to date on the latest technologies compared to services available in other provinces. The informant stated:

I have the impression that Home Care equipment for example, which is our version of assistive device program that are available in other provinces, it's very, very carefully limited in the kind of inventory that they have, that is - there are decisions made about whether they will stock X

device or Y device. Each device has to be carefully justified in terms of its benefit in limiting the movement of people in the personal care situations or greater personal care support requirement and so on, so economics are ruling that list of types of equipment that they have available. Some of their equipment is very dated and some of the - maybe there's a continuing need for some of that stuff, I wouldn't say there isn't but all the new technology that we're seeing at trade fairs and it just doesn't seem to be available from home care equipment. It's like, there's hospital beds and rocking beds and things from the 50s that are more and basic things like urinals and toilet seats and bath boards, all this sort of thing, whereas the assistive device program in other provinces, because perhaps they rely on retail end to actually provide the devices may have more modern equipment available through their program, and they have a greater variety of equipment available (012.IL p.16-18).

Choice Limited By Bureaucracy

Choice in assistive technology is also limited by the process of going through various agencies, by waiting lists and by the requirement for involvement by professionals.

One person described the waiting list:

Well, you also have to remember that they've got a waiting list - sometimes you have to wait months to get things that are very important to us - seating or other things, so there's not much sense of choice. You get what you need, what they will agree you need and what [occupational therapy] has, after their examination, indicated you need in order to be able to drive. There's not much real choice there, alternatives. I think there's a willingness to listen to ideas as to how to go about it and that's good. They will ask you, "Well do you think you'll be able to do it this way or do you think you're - " A lot of those questions have already been settled though by [Name] Therapy (012.IL P 12)

Respondents' Perceptions of Choice within the Present System

Some respondents were grateful for the present system as it is; though they would appreciate other options, they felt they were not necessities (002.IL, 008.NIL, 014.NIL).

These wheelchairs cost a lot of money and I think it's great that they give us a wheelchair to use ...lets get that kind or that kind whatever, hey just be grateful for what you get as far as I'm concerned. Sure, they have the light weight wheelchairs and they're very hard to get. If you put in a request you might get one but it might take you a long time but - I don't need it that desperately so I won't put in for one (014.NIL p12).

I would expect in my case if I wanted a chair that wasn't offered through the system, it would be my responsibility to get it, and I could afford to get it, so it wouldn't be a problem. But again my chair - it's got rib supports and modifications galore to it. You don't have a lot of choice. I know there are people out there, some of them want three wheel scooters, some of them want the Fortress chair put on something that looks like a car seat for some sort of esthetic reason. How practical they are I don't know. If it makes the person happy, fine. Most of the people I see with those things, I guess they were bought through insurance companies, MPIC (Manitoba Public Insurance Corporation) probably, but then you run again into the problem of who fixes them? (008.NIL p.13)

In the latter narrative, the respondent felt that there is not a great range of choice in the assistive technology market even if he were able to purchase a wheelchair directly. This may indicate that he has not been exposed to the wide variety of wheelchairs available on the market or may mean that with his disability there are few choices of wheelchairs available. The other concern he raised regards the repair service which is a very important aspect of using a wheelchair. The need to maintain parts for servicing a few models of chairs is also the primary rationale given by Wheelchair Services for not providing a wide range of choices.

One individual's narrative stands out in contrast to other comments surrounding choice. He felt that the present government system is adequate and that vendors are creating the consumer need for choice in products.

Like I say in Manitoba we're probably lucky compared to the other provinces. Maybe that's why the private sector is as adamant as they are about having government dollars withdrawn from certain programs because they can't break into the market place. The system is so entrenched that delivers a reasonable quality service, maybe not always the most if you want to call it - what a consumer would actually like or prefer, but at least you've got the product to operate. Of course the private entrepreneur sees that - they see where the money's being spent, and they see - they're telling us that we're the ones who should have choices - I mean that's funny when you talk to some of the private vendors, they're saying, well you guys should have choices, you should be able to get that money, you should be able to either come to us or go to Wheelchair Services. It's not me that's saying that, it's them that's telling me that I should be saying it. It's a neat way of cracking the market open - you're always going to find somebody that's going to say, "Ya, I think that's a good idea."

His narrative suggests some fear at the possibility of losing the present government funded program and the need for the government to fund products or services to respond to "basic needs". He continued:

Ya, the private entrepreneur - I don't have any problems with. I think there's room for them. I think if the consumer wants to buy their product that's suited to their own need, fine, buy it, no problem. There have to be some basic levels for needs. I think society, it becomes more of a social perspective in some ways, I think society has to take responsibility for meeting some of the basic needs. You can't rely totally on private ... market in my own mind. If you do, you're basically at the mercy of who's got the money (002.IL p14-15).

Choice can be facilitated if there is an alternative source of money. Respondents mentioned the following alternate sources which provided more choices: insurance including Workers' Compensation, Manitoba Public Insurance Corporation, VRDP or social assistance. The type of support and choices available seem to be dependent on the type of disability.

If you have the funding dollars available to you either through I guess through settlements, for example if you were lucky enough, and few might call it lucky, to be injured in a car accident or in a motorcycle accident or whatever, you did receive substantial income or Worker's Comp income or whatever. You have purchasing dollars directly at your disposal, so that part you're able to find quality equipment you need directly - it's your discretion what you want to buy. For the other consumers, they don't always have a choice available to them..... Some come through the income security program through - and then of course they require three quotes and I guess the lowest quote wins out whether it be the best product or not. It may not be a question specifically today. Two years ago that may not have been a problem, today they're getting more and more tight on the funding so the product that comes at the least price is the product you end up with, unless you can rationalize why you need the more expensive one. Of course it would require a professional to do that (002.IL p7-8).

Again, in the portion of this person's statement dealing with income security, the perception is that choice is limited to the least expensive item. For people who are able to work, there is funding for some equipment such as computers from VRDP. There is little available for those who do not work, who are not "involved in the community". The researcher assumes that the terms "involved in the community" means disability organizations, and other community organizations.

Several people offered suggestions that the system include more choice for those not eligible for insurance. Many respondents mentioned their need for a display centre where various types of assistive technology could be examined, tried out and evaluated including the assistive technology available from Home Care (003.IL. 012.IL).

I guess I've always wondered why we couldn't go somewhere and see what was available and have a little more choice and more information about alternatives and choice about what we were going to try. It's hard to deal in the abstract to decide what one needs. In my experience I discovered through these lengthy interviews with these people that I could benefit

from several low cost items that I had not been aware of previously. ... but I wonder what other things I don't know about that could make my life a lot easier, could make my life more independent, that if I had some better access to the information that I might choose to try and might ultimately benefit from. What I had to rely on was really the information that the people who interviewed me had available to them and the suggestions that they made to me resulting in several items that I used.

Interviewer: So you would like to see some choices in that government program?

Ya I guess, as a person with a disability growing older I know that I'm needing more supports to maintain my independence. I have throughout most of my life a good degree of independent living and independent self sort of sufficiency but as I get older I seem to be more and more reliant on technology and sort of staff support from time to time. At this point it's limited to five hours a week of staff support for home making and personal care but ten years ago I didn't have any and I can see that in 10 more years I might need more and likewise 10 years ago I didn't use a bath board or a raised toilet seat or grab bars and now I do. Ten years from now I'm may need more equipment, well if I was able to go somewhere and look at what was available, perhaps take things out on trial to check out, I might end up being better equipped in a more timely way with what I need to maintain my independence as the aging process goes on (012.IL p5).

The present system allows for little interaction between government funded and private sector vendors. One respondent felt that this limited the number of private vendors in Manitoba and thus limited the availability of options that could be viewed by consumers (012.IL). Several respondents offered compromise suggestions to mesh the present government funded system with the private vendor system to provide consumers with more choice.

Three individuals proposed a government program to support the purchase of assistive technology by the consumer (012.IL, 004.IL, 003.IL) This program could

provide support for wheelchairs or for other types of technology. In the case of wheelchairs, if the person did not want the Everest and Jennings wheelchair, the person could have the money that would have been allocated and would then supplement the rest of the required money from his/her own pocket (004.IL p.10) Another option suggested was to have the consumer pay for some portion of the maintenance of the wheelchairs (012.IL p.17)

Should People with Disabilities Have Choices?

The following data are all taken from one respondent's transcript. He was classified as an "IL" and felt strongly that informed choice was a basic human entitlement and that persons with disabilities should be allowed to take the risks that go along with making choices.

As far as my contention and the groups that I'm associated with ...that each body is unique and different and it's a matter of having an informed choice, the right informed choice but also experience of a variety of products as a basic entitlement, basic citizenship right (003.IL p. 7).

I find the system of wheelchair approval still quite antiquated and lacking in creativity and imagination and the fundamental principles of informed choice. the biggest issue there is to debate and examine is the problem of too many diversities and no backup, the company going bankrupt but that's part of life, to accept the fact that whether you buy toasters or cars or computers which disabled people can do on their own if they had the access to resources and take the risks in consequence with those. Somehow they can't do that with the assistive devices and I think it's become a bureaucratic system within rehab that has limited the choices to, in some cases anyway, to a fixed range, small range of products (.003.IL p7-8).

In the preceding example the individual alluded to the concept of giving risk-taking to the consumer, even if that meant taking the risk that an assistive technology vendor may go bankrupt. The same respondent continues to discuss choice in terms of who should be making choices with respect to assistive technology. He stated:

There needs to be informed choice the Society [for Manitobans with Disabilities] should provide informed choice to people, the best relationship would be professional consultation and options, but not through the same bureaucrats who control, limit the dollars and choices so it's a whole gatekeepers system that's under review and needs to be examined.... There needs to be accountability, there also needs to be a transfer of risk and responsibility to individuals who make open choices and to bear the consequences of those, and that may fly in the opposition of do-good agencies and the professional status who may feel that in the training and their mandate that they're responsible for the right choice made and their adjustment as to what the right choice is. So I think there's still a diversion of opinion between who can make the final choice and who is the consultant and who is the decision maker, and that is what the [Federal] Social Review is getting into right now (003.IL P.9).

Conclusion: Choice

The respondents' narratives indicated that "choice" in assistive technology is not available to most citizens in Winnipeg. Choice is limited by bureaucracy including layers of bureaucrats, professionals and waiting lists. Choice is limited by the amount of income the individual has, especially for those who work at lower paying jobs. Choice in the government-sponsored program is limited by pre-determined regulations defining the type of equipment which will be distributed. Much of this equipment is out of date, according to the consumers interviewed. Some equipment, such as wheelchairs, has been purchased

from the same manufacturer since the program was established.

This limitation in choice contrasts with basic principles of the Independent Living Movement where informed choice is viewed as a basic citizenship right. Respondents offered a solution: to provide the consumer with an amount of money equal to the cost of the equipment now provided from the government agencies. Consumers could then purchase their own equipment, thereby having some choice. A problem arises with wheelchair repairs. Solutions have been offered such as a system allowing consumers to pay for a portion of the repairs of chairs which they choose. Another solution might be to establish an arrangement with vendors to do repairs. However this latter approach was not discussed by the informants.

Professionals as Barriers or Facilitators to Accessing Assistive Technology

One of the questions asked of the respondents concerned their experience with assistive technology professionals. References to “professionals” were purposely not defined by the researcher during the interviews so that categories would emerge naturally in the respondents’ discourse. The most frequently mentioned professionals were occupational therapists and rehabilitation engineers, followed by physicians, and physiotherapists. Most of the discussions focused on the roles of occupational therapists, possibly because the respondents knew that the interviewer was an occupational therapist. This may also have occurred because in Manitoba, occupational therapists are often the primary assessors of assistive technology requirements. Because occupational therapists were the main professional group discussed, the researcher analysed this portion of the

data in relationship to the client-centred approach proposed by Law, Baptiste and Mills (1995). A true client-centred approach seems to approximate some of the principles of the Independent Living Movement, hence this analysis.

The current philosophy of Canadian occupational therapists is that the profession practises under a “client-centred” approach. Although the term had been used in Canada for over a decade, it was yet to be defined until the work by Law et al (1995) was published. Law et al (1995) have attempted to define the term and to provide categories of what should be included in a client-centred approach. According to Law et al, a client-centred approach is defined as

an approach to providing occupational therapy, which embraces a philosophy of respect for, and partnership with, people receiving services. Client-centred practice recognizes the autonomy of individuals, the need for client choice in making decisions about occupational needs, the strengths clients bring to a therapy encounter, the benefits of client-therapist partnership and the need to ensure that services are accessible and fit the context in which a client lives (Law et al, 1995,p.253).

Law et al (1995) could find very few occupational therapy studies that examined the effectiveness of client-centred practise; they described a number of concepts which form the underpinnings of a client-centred approach. These include autonomy and choice, partnership and responsibility, enablement, contextual congruence, accessibility and flexibility, and respect for diversity. In their study of these concepts, Law et al (1995) have combined definitions from various sources including some from the Independent Living movement. (Law et al, 1995 p. 252). These concepts are discussed here, not only to demonstrate the contrast between theory and the consumers’ description of the practise of occupational therapy, but also because many of the concepts could arguably be seen as

similar to the Independent Living principles of consumer control, choice, decision making, and risk-taking. The word “client” would be replaced by the word “consumer” in Independent Living language. For the purposes of this study, this comparison is therefore important since one of this study’s objectives was to determine if assistive technology services were provided in a manner which was consistent with the principles of the Independent Living movement.

The data from this study showed that the consumers' perception of the performance of professionals (occupational therapists) does not reflect the client-centred approach espoused by the profession. Many of the informant narratives emphasized a clear power differential between the therapist and the client with the therapist having more power. Often the consumer perception seemed to be that one right answer was offered from the therapist without consideration of the consumer’s (client’s) needs.

To make this comparison, the researcher outlined each of the categories considered by Law et al (1995) with a description of the theme as they defined it. These categories from the Law et al (1995) client-centred practice definitions were then analysed and compared to data from the consumer narratives to contrast theory and practice. The following elements of the client-centred approach will be discussed: a) Autonomy/choice; b) Partnership; c) Enablement; d) Contextual Congruence; e) Accessibility and Flexibility and f) Respect for Diversity.

The data will be used to explore the perceived barriers created by professional occupational therapists in interactions with their clients. This will be followed by a summary of consumer suggestions for change which would enable occupational therapists

to work in a more “client-centred” or consumer-focused framework.

Autonomy/Choice

According to Law et al (1995 p. 251) the category “ autonomy/choice” emphasizes that: “clients are experts about their occupational function. Only they can truly understand their experiences of their daily lives, express their needs and make choices about their occupations.”

The following are some examples from the data in which the service provider did not acknowledge the autonomy of the consumer/client.

The respondent in the following passage described what it was like to learn from an occupational therapist how to care for herself after having a brain injury.

They don't live in my body, they don't know my body like I know my body. I know what I need and I know what I need that would help me, they don't. Actually, I'm not saying they're not good because they are, but as I said before I know my body better, I think I know what I need more than what they do and sometimes too when - okay it goes through O.T. when I was in the rehab they said we'll do this and this and this - I say I can't. I do it my way because I know how to do it. Well,they said “ that's not the way you're supposed to do it” , I said, I don't care that's how I do it because that's the only way I can do it (014.NIL p.4) .

Another individual described the decision-making process when he received hand controls for his car:

As far as hand controls went, it was a matter of I guess it would be CPA [Canadian Paraplegic Association] counselors and O.T. assessment and the

equipment was identified that I needed and the equipment I have works very well. But it's a matter of making sure you get the right - I guess you have to speak up but for the most part to get the equipment I needed

Interviewer: *What do you mean, what happens if you don't speak up?*

Well, you may end up with equipment that "they" feel is most appropriate rather than the equipment that you find appropriate (002.IL p.4).

Lack of choice was identified by this consumer who received information from an occupational therapist at the time of his spinal cord injury:

The biggest problem you've got, at least I had at the time, is all the information you needed to know was like here's one sheet that identifies the product you need, there it is. I didn't get four or five sheets and four or five different products where I'm able to say, well no, this product looks like it would be more usable than another product. It's like the sheet that had the product on it was the one that I was given, and I didn't know another sheet existed until such time as I started working in the field, then I found out, hey wait a minute, there's a lot more than just one device in one specific field (.002.IL p4).

Partnership

According to Law et al (1995), in client-centred practise, the goal of the client-therapist relationship is an inter-dependent partnership. Power is defined as a process by which the client and the therapist achieve together what neither could achieve alone (Crabtree & Caron-Parker, 1991, Law, 1991). The following excerpt demonstrates the power differential that one individual felt when dealing with assistive technology professionals. The individual's narrative below has been cited before however it was important to repeat again in this context. Although he has had a disability for several

decades and is a leader in the Independent Living movement, he still felt intimidated by professional power.

I think I was probably a little intimidated, like I say the power to grant you these devices are to certify that you get a license is absolutely not your own - it's absolutely vested in the people and there is a system of trust and collegiality of the various actors.... Because they work together a lot on these things and they vest their confidence and credibility in each other, it's a little network of people, and so they all are part of the gang. If you get somebody's nose out of joint you're not going to - doesn't improve your chances of getting that license. So if an O.T. tells me I need a cushion behind my back, I don't think I do, I wonder if it isn't dangerous but if she's strong enough on it I'll probably go along to try to move the process along and then throw it away later when I confirm in fact that it's a risky thing for me (012.IL p.8).

The previous passage and the following demonstrate the lack of feeling of partnership in the therapist-client relationship.

This is what I find that - with OT I think it would have helped me a lot - say if an OT would show me one way, okay I can't do it, so how about this way and we work together, that would work super. But how many people can do that with an OT? (.014.NIL p.5)

The last line of this passage is quite disturbing when one assumes that occupational therapists are supposed to work in a partnership manner according to the client-centred model of practise.

Enablement

According to Law et al (1995), in the client-centred approach, enablement means

that the therapist works with the client on issues defined by the client. The therapist is valued not only for technical competence, but also for caring shown by truly listening to the client.

In these interviews, this willingness to listen seemed to vary according to the personality of the therapist.

They're not always willing to listen to what you think you can do. Depends on the therapist you get. Some of them are quite open to listening and experimenting and trying out, and others have very definite ideas about what you can do and what you can't do somehow, or what kind of device would work for you and what wouldn't. They may not - and then another therapist will be quite open and say, "Oh you think this other device - well let's try it or we could maybe explore that." They're willing to work a little more with your own judgements, intuitions and so on and some aren't. I would say about 50 - 50 in terms of the attitude of the people that I've encountered in that particular process (.012.II).

Contextual Congruence

Contextual congruence is defined as "The importance of the clients' roles, interests, environments, and culture are central to the occupational therapy process within client-centred practise" (Law et al, 1995 p. 252).

The following example portrays a lack of contextual congruence. The respondent was not interested in "wasting her energy in washing herself", she preferred to delegate this task to an attendant so that she could have the energy for her productive roles. However, the therapist did not take the client's roles, interest or environment into consideration.

The ones that I didn't like so much - I think really listening to me and listening to what I feel that I need and going with my direction more than

with them just coming in and making quick assumptions, stretching my arm out and saying "oh you can do this" without even recognizing many aspects of the way I live my lifestyle, looking at maybe my strength or whatever. I'll give you a good example of one person giving me something to help me take my bed bath and she gave me a stick with a sponge on the end of it and it was completely - I couldn't lift up the stick, the sponge was - when it got full of water I couldn't lift it and this was a person who didn't listen to me. If I said, I don't think I'm going to be able to lift that, it was "Oh yes, you just can try and you'll be able to do it." You know that kind of an attitude and it was - those kinds of people to me aren't very helpful. So I like people who allow me to be part of the partnership and planning and I get along well with those people (009.II p67-80).

Accessibility and Flexibility

Accessibility and flexibility are defined as "*Services are provided in timely and accessible manner...Therapists work to enable clients to access services with a minimum of bureaucratic red tape*" (Law et al, 1995, p. 253)

This idealized principle contrasts with the experience of the respondent quoted below who had to overcome bureaucratic requirements and be on a waiting list to access service. One may argue that barriers in this situation were beyond the occupational therapist's capacity to intervene. However, according to the client-centred model, the occupational therapist should be aware of and evaluate the accessibility and flexibility of his/her services. The individual stated:

When I first decided I wanted a special cushion under me, the first thing I had to do was get my doctor to say I needed this special cushion, so I went to her and she said, "Okay, if you want a special cushion, I'll sign this paper for you." She sent it to the Seating Clinic and I waited for about three months and never heard anything from these people so I called them - they didn't have anything on record.I went over myself and talked about what I wanted and

now I had to get this doctor's statement anyway. So I had to get back and get another doctor's statement and they saw me within a week after that. I went over to the Seating Clinic and this was the most bizarre thing I ever went through, it's probably the most frustrating experience. The doctor was sitting there in one chair, she never got out of her chair all the time I was in the wheelchair, she just sat there. There was an O.T. there, I'd never seen this woman before and didn't do very much either except look me over, and somebody from the Rehab Engineering Department - he was the only one who touched me and actually felt around to get some ideas on what I needed... I knew for sure that wasn't going to work (009.IL, p. 10)

Respect for Diversity

Law et al (1995) define the respect for diversity as: "Intervention based on clients' visions and values demonstrates a respect for the diversity of values that clients hold. It is important for therapists to recognize their own values and not impose these values on clients" (p 253).

The individual in the next passage described how the occupational therapists clearly disregarded her needs as a teenager. Not only did the device look unsightly to this individual, it offered little in the way of function compared to what she was capable of doing. She was able to manipulate objects using a combination of her teeth and hands, yet the therapists insisted on finding another solution. It is significant that this woman, now in her forties, still expressed her feelings so strongly around this experience.

As a child I remember them [occupational therapists] saying, oh you need this and you need that, you need this because I'm one handed and so at one point I forget what they call it, but they had this gizmo thing designed that you put your arm in....so they devised this contraption that I always felt made me look like robo cop or something, and you had to put your arm in this basket and it was on two bars that you could swing with your shoulder. It was ridiculous and I kept saying, no I don't need it, I don't use it, but they felt oh no, you should try it. ...It's not really, to me, worth having this God awful ugly thing, you're talking about image of someone

who is high school teenager like Hello, but they wouldn't listen so they spent all this money devising it and building it and putting it together and then saying, yes you need it, it will really strengthen your arm and give you much more mobility and ability in that hand. (001.IL p.9 396-440).

Suggestions for Change: Respondents' Strategies for Change to the Client (Consumer)-Professional Relationships

The previous examples showed that there is a contrast between the client-centred philosophy and the actual practise of occupational therapists in delivery of assistive technology services. The consumers themselves offered advice on how to change the service delivery. This section will also be organized according to Law et al's (1995) conceptualization of components of the client-centred practise: a) autonomy/choice; b) partnership/enablement; and c) access/flexibility.

Autonomy Choice

The following examples demonstrate two important points. First, the respondents recognized that there is currently a spectrum of opinion among professionals in terms of maintaining "openness" in working with the individual as an autonomous person. Second, respondents emphasized that there has to be some recognition by professionals that consumers are "experts" about their own circumstances. One stated:

...so much depends on the personalities of people whether they want to apply it or not. I think ... it's either because of ignorance or they still haven't grasped the idea that disabled people have a head on their shoulders and can think for themselves. I think there's room for it to happen, it can happen, there's no reason why it shouldn't happen, but I think the people in those systems have to change their attitude a bit (009.IL p.6).

The O.T. that I mentioned with [Specific therapy service] to me that's pretty encouraging because she certainly changed my views on professionals to some degree. I knew that professionals could respond to me the way I wanted to be responded to and I knew it was possible after meeting with her. She's very, very good. (.009.IL p.7)

In the following narratives the respondents emphasized that if the consumer-therapist relationship is to work as a two-way process, there needs to be an attitude change by therapists which includes listening to the client and seeing the consumer as having some expertise.

When you want choices you want people to listen to you and that sort of thing and it eliminates getting advice from people. There are times when I want to listen to them too and I should have that choice. If I don't know the answers and I recognize I don't know it and I need to get more input then I think I should be able to receive it and I think they should be prepared to give advice if they can, but they have to listen to the consumer as well and it's a two-way type of thing, it's not one or the other (009.IL p.11).

I think the things that have to be stressed is people need choices and there should be more than one kind of any device. I also believe in the self-management buying where you put the money in the hands of the consumer and they go out and purchase their own devices. Certainly attitude change should take place. There is no person who knows what they need better than the person themselves and unless people cancome up with devices that are very good unless they're able to listen and hear what the person's saying. (001.IL p.3)

Partnership/Enablement

Consumer perspectives on more co-participation are provided in the following two examples.

So much depends on the person working in a particular system. I don't think it's so much the system sometimes. For instance I have received some help through ... and it happens that the occupational therapist that

I'm working with right now is - she's extra-ordinarily consumer oriented and is very open to listening to me and getting my ideas and I feel that we're working together as a team... However, I have worked with other professionals in the same system and I haven't received that kind of an attitude (009.II p.4)

....because the thing is with an OT it should be a two-way - side by side thing. Maybe OT knows one way but the person - it might not be suitable for the person so therefore find another way to do it, and if they can do it - great, no matter how they do it, no matter how hard it is but if they can do it that's the main thing (.014.NIL p.3).

The following is an example of a partnership between the consumer and the therapist described by one informant.

Ya, I use the [Specific Agency]. Again, I find those people pretty extraordinary. They also work with me and take direction from me and most of the time they won't even deal with me unless I can be pretty specific in terms of what I want. If I go in, and say I think my arm needs to come up a bit higher, that's usually not good enough for them, they say they have to know how my arm should be placed but they will fix something if they know exactly what I want. Then I have to start thinking, well I need the arm a bit wider and I need it lifted on one angle and I need an indentation to fit my elbow and I'll get them all these very specific instructions and they will carry it out for me, so that's quite good.(009.IIp2)

Access and Flexibility

Respondents offered advice on how to make the delivery system more accessible, flexible and offer more choice. A model system would entail professionals sharing control, decreasing the layers of bureaucracy and providing an accessibly located display centre where items can be viewed and tried out by the consumer. One respondent stated:

You shouldn't have to go to a lot of professionals...to make decisions about this equipment. I think sometimes in a highly specialized area it may be necessary but I think it should be operating more like you're buying your car, like you're buying any other product that you need. I would say probably about 90% of disabled people know what they need and it's just a matter of going and getting it. They don't have to go through a whole system of people assessing them, evaluating them and this kind of thing. ... most disabled people can make the kind of decisions that I made about the wheelchair just the same way as I do and they should have the same opportunity and the same flexibility to do that (.007.IL p6) .

There is always going to be a small percentage of people that require more trained expertise, but the system should be that it caters to a small number or cater to everybody and then provide a way of more intensive technical equipment or professional services to the small number who need it....but the system needs to be more flexible, it needs to have more choices for disabled people and it needs to be simpler to access the technical equipment.I think there should be a place to test out the equipment....disabled people make the kind of choices that they need to and have more control over the situation. I think it would cut out a lot of time that professionals spend on these things which I don't think is always necessary (.007.IL p8).

An interesting point to consider is that an assistive technology display centre would take away some of the professionals' power as some of their knowledge will be shared by the consumers, thus removing the “mystique” associated with assistive technology. However, the establishment of a centre would benefit both consumers and professionals because consumers would be better informed and professionals themselves would have a place to see the equipment they now can view only in catalogues.

Conclusion: Professional Relationships

This section on relationships between professionals and consumers has focused on interactions with occupational therapists as professionals, mainly because most

professional encounters discussed during the interviews involved occupational therapists. It is hoped however, that all professionals who deal with assistive technology can learn from these data. The data were analysed according to the client-centred model described by Law et al (1995) because of the researcher's perception that it incorporates principles which are consistent with Independent Living principles. The analysis illustrates that some respondents' experiences with occupational therapists have been problematic. However, consumer narratives also provide examples of positive encounters and suggestions for improvement in this area.

Relationships with Assistive Technology Vendors

Eight of the 17 people interviewed had dealt with vendors to purchase equipment unavailable from the government program. Although some respondents had purchased equipment from non-traditional suppliers such as machinists or upholsterers, the discussion around vendors generally focused on suppliers of specific assistive technology.

Some respondents commented that vendors offered more choice in the system (.007.IL p7), treated them more as a customer than professionals did (.004.IL), and were understanding of the needs of the person with disabilities (.001.IL). However, the overall picture painted of the vendors was less than favourable. As one individual perceived it, there is a lucrative market for this type of product. In referring to vendors "*The attitude sometimes is good and sometimes it's rotten*" (017.NIL p.7).

Two main themes were identified from the data which characterize the consumers' experiences with vendors as perceptions of: a) pushing the sale and b) not consumer

oriented.

Vendors Viewed as Pushing the Sale

Pushing the sale was a common theme in these narratives. Respondents commented that vendors would try to sell their product as “best”, and therefore not discuss any other product options or fully explore the needs of the consumer (016.IL). This approach on the part of the vendor would lead people into buying a product not suited to their needs. Often, a specific vendor was the only provider of particular items in Winnipeg. This monopoly position left the consumer at the mercy of the vendor and meant there was little latitude to negotiate price or service terms. Some consumers felt that the vendors would try to sell anything to make a sale (0011.NIL) .

One person commented that often the need for equipment could come at a particularly vulnerable time in the life of the consumer. Specifically at the time the person first acquired a new disability, vulnerability occurred in situations “where emotions are taking the forefront over rational thought” (003.IL).

I am afraid that it's still not as objective and neutral but people have to learn the hard way that if there are two or three devices that you happen to be getting commission on because you're a vendor for those two products, that you're in a vulnerable state or family members are in a vulnerable state and you're feeling guilty because somebody has an injury or grandma is now suddenly using a wheelchair and everybody's feeling bad about that, she's upset, you may just be easily talked into by a local sales person (003.IL p.9).

Another respondent, who also works as a counsellor for persons with disabilities, commented on his need to protect consumers from “snow jobs” by vendors (016.IL).

Overriding all of this was how very expensive the equipment was (017.NIL, 007.IL). The

following examples further emphasize these points:

One fella I know came to me after he bought a lift and he came here and he said, "this thing is giving me a real headache." He said, "I thought I was going to be able to do this, that and the other thing." I said, "well, if you wanted to do that you should have gotten this kind of lift because it doesn't come in this far - whatever, so he had to go back to the vendor and of course the vendor didn't want to take the lift back and that guy learned an expensive lesson (.016.IL p.12).

In the next example the individual had ordered an \$8,000 power wheelchair to go out to places where normally he would fatigue if he used a manual wheelchair. Ultimately, it was too large for his van and his house. The respondent did not feel he was given all of the information necessary for him to have made the right choice. He now recognizes that he could have ordered a smaller wheel-base for the chair with the same size seat.

Personally I feel that they should have said, "Are you sure you want such a big chair?" I think that they should have said, "Do you realize that this thing is so many inches long or whatever or it's going to restrict - whatever. Why don't you look at doing this, that or the other thing?" Personally I think that they should have done that but they didn't and I guess it's water under the bridge. What are you going to do except chalk it up to experience. (016.NIL p. 13)

Two respondents' narratives portray vendors with a monopoly as overbearing and trying to sell anything.

I found that they were overbearing, they always have the right thing for you, there's no place else to shop. When they brought a scooter out for me to try he had the contract written out, signed with tax and everything - signed, dated, etc. He came back ready for me to give him a deposit cheque, he was that sure that he had sold it (0011.NIL p 5).

I find that people will try to sell you anything and tell you that it fits your needs and it won't. Having worked with [vendor name] and having worked with the various dealers and because I've taken three pre-med courses.... , I know that you have to be a very informed consumer. If you're not an informed consumer then you might as well forget it, because people will

take advantage of it. (0011.NIL p10)

Vendors Viewed as Not Consumer Oriented

Another theme identified was the perception by some respondents that vendors were not consumer oriented. Although one would expect that if the consumer was holding the purse strings, the vendor would be willing to talk to that person, respondents indicated that this did not always happen. One individual described how the vendor refused to deal with him and would only deal with a therapist, even when the individual complained about problems with the product. The vendor would communicate with the consumer only when the bill had to be paid (017.NIL).

But they don't want to help me. They had my money already, are they going to have any more of my money? Not likely, except that if I need something they're the only source to get it... Then I'm stuck, I mean I'm not really stuck because I can go elsewhere. I can go to Ontario if I'm willing to go to some lengths.... that would be sort of spiting myself which I'm not likely to do, but if I have a choice I'm definitely not going there again. I've seen that in a number of instances people out there doing business but they're not really doing business. It's crazy, it really is.... That's right, they dealt with the therapist. She's the one who put the order in the first instance and she's the one who arranged to have it delivered - I had no dealings with them except when they wanted a bill ... It didn't go through the agency, they billed me directly. They had my address, they know where to come and in fact when I didn't pay them they started to give me a hard time, they invoiced me with interest because I didn't pay them and I had to get back and send them a letter and say, listen it wasn't satisfactorily done, it had to be returned to you to readjust it. When I get the thing then I'll pay for it, so when I got the thing, I paid for it (.017.NIL p7).

Another consumer explained how the vendor did not seem to appreciate her questions about the product and she felt she was supposed to be “dumb” in their eyes. (011.NIL).

That particular scooter had a rubber edge on the floor board and that

rubber edge was like a cut pipe. I drag my foot when I get off and I dragged my foot across the top of it The rubber edge came off of it and that is uncut raw steel. When I asked him about it he was totally unconcerned. I wasn't supposed to know anything like that, I wasn't supposed to know anything about it. I also asked him about the running of it. I was supposed to be very, very dumb about how things motors and things like that run. He wasn't going to give me any answers (.011.NIL p.5).

Respondent Proposals for System Change Involving Relationships with Vendors

One respondent felt that people with disabilities were gradually becoming more informed about product choices. It was suggested that consumers have to know what they want when they go to the vendor. However, many felt that there is a lack of information sources. As well, it is virtually impossible for the consumer to keep up to date on new product information. This same person suggested that there is a need for an unbiased assessment and product recommendation from someone like an occupational therapist or a CPA counsellor (016.IL) However, another person contrasted this suggestion with the comment that many people who go through the professional system still do not have equipment that works or don't have any equipment at all (003.IL). A product display centre where a variety of products could be seen and assessed by the consumer was suggested by many respondents. It was also suggested that consumers have to realize that salespersons are trying to sell a product (003.IL). This may mean that educational sessions should be made available to consumers about how to deal with vendors. This could be facilitated by Independent Living Resource Centres, other consumer organizations and by occupational therapists, who adhere to the client-centred approach.

Conclusions: Relationships with Vendors

The central point emphasized by respondents was the need for a more global change in mind set. People have all been so used to the medically oriented system in which the person with the disability was not seen as having any decision-making power. The impact of this perspective was reflected in the description of the vendor only wanting to deal with the therapist. Perhaps, consumers expect more information and opportunity for consultation from the vendor than is realistic. In conclusion, consumers with disabilities must somehow become better informed and vendors must learn how to deal with persons with disabilities as customers, rather than dealing solely with therapists. The development of a product display centre would provide consumers with information before they purchased technology from a vendor, ensuring that they are better informed.

The Built Environment as a Determinant of Acquiring Assistive Technology

Assistive technology cannot stand alone without considering its interaction with the built environment. In many cases, assistive technology alone cannot provide independence; it is inter-dependent with the built environment. In this case, the built environment means both the interior and exterior built environment. For instance, an individual may have a state of the art wheelchair, however, if the person cannot get around in his community due to architectural barriers, the wheelchair itself is offering little in the way of independent mobility. Although the theme of the impact of the built environment was not included in the original questions for the interview, the topic did come up

naturally in some of the interviews. The two dimensions discussed by informants were the impact of the a) outdoor built environment and b) indoor built environment.

Outdoor Built Environment

The outdoor built environment can either facilitate or handicap the user of assistive technology. One woman described how she was forced to travel on busy streets to get to the local mall because sidewalks were “too bumpy” (014.NIL). Not only is the road more dangerous because of the traffic, there are other dangers such as broken glass. She described the interaction between her wheelchair and the barriers in the environment.

Last year my manual wheelchair had tubes in the tires, these marvelous people that throw glass on the road, throw bottles on the road, okay you're bopping along and trying very hard to avoid glass, there's so much you can't see and you roll over the glass - I would phone them [Wheel Chair Repair Services] at least once a week - "I need new tubes,- flat tires all the time". They finally said to heck with this and they gave me solid tires. They're bumpier but hey I would rather have a bit bumpier ride and not have to phone every week to give me new tubes.(014.NIL p.6)

In this case the solution adopted by the provider was to change the technology to match the demands of the environment: e.g. change the pneumatic tires to a solid rubber tire.

Another danger of riding on the street is described in the following narrative by the same person. She also noted that if the wheelchair controls suddenly malfunction while the individual is driving on the street, she is in danger of running into traffic.

I've had to have people push me home because one day I almost hit a bus. Something was wrong with the control and it wouldn't go straight and I was crossing [a major street] and I'm trying to go straight and my chair

headed almost to the bus and the poor bus driver - oh my God and I said I'm sorry, it's my wheelchair I can't control it so somebody had to push me home because I couldn't go in a straight line (014.NIL p.6).

A qualitative study by Cooper and Hasselkus (1992) found similar interactions between assistive technology and the built environment. Informants interviewed in this study indicated that their desire to access their neighbourhood would override their concern for safety. They therefore reported they were involved in risk taking as they travelled alternate routes which were unsafe for users of powerchairs. Shearer (1982) and Lifchez and Winslow (1979) have also documented this risk-taking behaviour related to accessibility and mobility.

Parallel themes of balancing risk and access were identified by respondents in the present study. One person described the inaccessibility to her bingo hall and the consequences of this for her own risk taking behaviour. She described how her “accident” contributed to the needed environmental change.

Actually I feel great about it because it was at bingo and they had a little step like that so my friends go up no problem and I thought I can do it too. I gave a what for it and I just tipped over backwards and I hit my head on the cement so they came running out to see if I needed an ambulance to take me to the hospital, ... Two weeks later they had a ramp in there. I don't mind, I wasn't hurt and I'm glad it happened because if it wouldn't have happened they wouldn't have the ramp there yet. So okay, fine, so be it (014.NIL p12).

If independence means being able to participate in the community like everyone else, and if assistive technology will aid in achievement of independence, then accessibility of the community is of primary importance.

One area not discussed in these interviews was the topic of the impact of climate

and its importance in understanding the use of assistive technology. In Winnipeg, the harsh winter climate seriously restricts assistive technology usage. It influences the living arrangements of persons with disabilities. Many people opt to live in apartment blocks with underground parking facilities, or overhead skywalks to shops and services. The interaction of climate and assistive technology would be another area to explore in future studies.

The Indoor Built Environment

The interaction between assistive technology and the environment also involved descriptions of the impact of interior space. One respondent who lives in a Fokus Housing unit (accessible suite) is able to walk with a walker, but uses a wheelchair for travelling longer distances. She described some of the difficulties that she encountered inside her apartment. The edge of the carpet created a hazard for her until she demanded that it be fixed. This particular Fokus unit did not have a conventional oven and only provided a microwave oven. The researcher noted that this might indicate a method of controlling the risks involved with oven use. The respondent stated:

*My microwave is not where I can use it. The door opens the wrong way, it's off in some little corner, I can't get food from the cabinet to it or from it to the table.
.... my carpet has been changed... they had a rounded edge going between the carpeting which is industrialized carpeting for the purpose of the wheelchair, which causes rug burns when you walk in bare feet, but the metal strip that went between the linoleum and the carpeting was a rounded beaded edge and even hitting it with the bigger wheels on my walker, you would spill anything that you had. I had them - they were still doing some fixing in here*

and I demanded that they put the flat edge on. I told them if they didn't that I was going to get somebody who had a concrete driller and I was going to drill the hole and put it in myself and send them the bill because it was too dangerous. (reference after following passage)

She also described her experience of having difficulty convincing her landlords that she needed a grab bar near her toilet. She went on to describe patio/balcony access in the apartment block.

I've got the patio door which I can't use at all because I can't get over the top of the heater to get out to the step and then there's the step that I can't use because there's no railing, down to my patio, which is out there under the snow... all of them upstairs have been retrofitted for the patio door and everything so they can get their wheelchairs in and out on the balcony.

Interviewer: Why can't you do that?

R: *Because I was told it would upset the look of the apartment*

Interviewer: What about if they could make your door more at ground level like the other people's upstairs?

R: *Ya, that would be fine but then you see I'd still mess things up by having to have railings (011.NIL P6-7).*

This respondent's experience suggests that even in a Fokus Unit, which is supposed to be accessible to persons with disabilities, there can be accessibility problems. This individual's experience in dealing with managers in requesting that outdoor railings be installed also shows the attitudinal and organizational barriers which impede change.

Conclusion: The Impact of the Environment

The environment greatly influences the use of assistive technology. Physical accessibility has a great impact on the use of assistive technology. The environment and assistive technology go hand in hand because both influence the potential for independence. Although the built environment was not initially selected as a focus for this research, respondents statements suggest that there be further study in this area.

Relationship of Access to Assistive Technology and the Individual Environmental Determinants of Handicap Situations and Social Participation Model

The intervening conditions of information sources, cost and eligibility requirements bureaucracy, choice, relationships with professionals, relationships with vendors and accessibility of the built environment can all be classified under environmental factors according to the Whiteneck & Fougeyrollas (1996) model. Most of the data documenting consumers' perspectives on assistive technology can be classified as “barriers” rather than “facilitators”. The model hypothesizes that barriers in the environment will lead to handicapping situations whereas facilitators will lead to increased social participation. The model further emphasizes that each of the environmental factors (or intervening conditions in this study) can then be categorized in terms of micro, meso, and macro environmental factors.

According to Whiteneck & Fougeyrollas (1996), **micro** environmental factors are defined as the

immediate personal environment of the individual with the focus on physical and functional characteristics. The **meso** level consists of the broader community environment and focuses on the attitudes and beliefs held by people which the individual encounters. The **macro** level consists of the broadest societal environment focusing on policy issues. The intervening conditions described in this study can be classified under these three categories. For instance, the fact that the person is lacking in assistive technologies can be classified in micro environmental factors since doing without these will affect their functioning. Architectural barriers can be classified under the micro environment but also under the macro environment. The macro environment classification here may be reflected in the absence of laws and organizational policies regulating architectural barriers. Cost, eligibility requirements, problems of dealing with complex bureaucracies and lack of choice all relate to the macro environment of policies and laws. Relationships with vendors and professionals relate to attitudes of the meso environment. Many of these will, of course, over-lap. For instance, attitudes (meso) will influence policy (macro) which all have impacts on the person's own (micro) environment.

The intervening conditions can also be evaluated in relationship to the five characteristics of the environment which the model defines as having significant influence on handicap. These include: **accessibility, accommodation, resource availability, social support, equality of opportunities.** (Described in Chapter 3, Table 4, p. 34.)

Accessibility addresses the question "can you get where you want to go?" The answer from data gathered from respondents is that there are still barriers in the built environment that have an impact upon the use of assistive technology.

Accommodation addresses the question “can you do what you want to do?” It is defined in terms of the equipment, services or modifications of tasks which facilitate full participation. The data from this study indicate that most people were involved in a range of work, play and leisure activities. However a central question is how much this range of activities could be expanded if individuals had access to the full range of appropriate assistive technology.

Resource Availability addresses the question “are your special needs met” and is defined in terms of availability and provision of services and resources including income security. This category focuses on the degree to which the extra resources needed by a person with a disability are available. From the respondent interview data it seems that people do not have all the resources they require to acquire needed assistive technology. There are limitations in government sponsored programs and insurance programs. People with disabilities have less income, but sometimes need to purchase assistive technology to supplement that provided by government sponsored programs. There are few tax incentives available to enable the consumer to recover the costs of assistive technology.

Social Support addresses the question “are you accepted by those around you?” The data showed that relationships with professionals and vendors were perceived by many informants to be less than favourable. Vendors and professionals did not view the consumer as a partner and an expert in his/her own right. The perception among some respondents was that governments paid little attention to issues of environmental access and funding of assistive technologies. This may be reflective of general social attitudes toward persons with disabilities.

Equality of Opportunities addresses the question “do you have the same opportunities as others?” The respondents’ statements clearly indicated that they perceived that they did not have the same opportunities as others. Most identified inequalities in the opportunities they had had. For example those born with a disability or who acquire a disability which is eligible for insurance coverage do not have the same opportunities for acquiring assistive technology as those who have an accident. As well, the expense of assistive technologies places many consumers at a disadvantage. While most people in society take for granted the expense of purchasing a vehicle, a person with a disability may incur extra expenses generated by the need for a van and various modifications. These extra expenses are not completely reimbursed by government-sponsored programs in Manitoba, thus many people are forced to rely on public transportation. Some people cannot afford to purchase an elevator to make their living accommodations accessible. Therefore they do not have the option of living in a house and must live in an accessible apartment building.

Publicly supported health care is increasingly being rationed. Rationing and prioritization of program responsibility for the provision of assistive technology may further reduce the level of support provided by government. With diminished access to assistive technology, persons with disabilities are less able to participate in society, including the work force. To maximize participation, productivity, and independent living, government and insurance based sources of support should support a wide range of technology used in all life spheres. Assistive technology must be classified as a basic

requisite of independent living rather than as a medical or vocational entitlement.

In summary, if one examines the data from the respondents in terms of the analytic framework developed by Whiteneck & Fougeyrollas (1996), it might be observed that barriers in the delivery of assistive technology create a handicapping situation for many persons with disabilities.

Overall Summary of Chapter 6

The objective of Chapter 6 was to discuss the intervening conditions that create barriers or act as facilitators in the process of “acquiring assistive technology” (the core phenomenon). The following intervening conditions were discussed: information sources cost and eligibility requirements, bureaucracy, choice, relationships with professionals, relationships with vendors, and the accessibility of the built environment.

How these intervening conditions create barriers or facilitators to getting assistive technology is summarized in Table (4) p. 155-156. The third column of the table shows the researcher’s interpretation of the impact of the various barriers on persons with disabilities. For instance, a lack of information sources leads to a restriction of informed choice and inflated costs. Complicated eligibility requirements lead to lack of choice, inequitable distribution of assistive technology and limitation of the consumers' human rights to equal opportunities. The need to deal with complex bureaucracies leads some consumers to doing without assistive technology rather than going through all the steps required to assess need and provide services. Respondents also identified power differentials between the consumer and the professionals, and lack of accommodation of the consumers's capacity for responsibility and risk taking. Lack of choice limits what is

available to consumers and limits their independence. Attitudes of professionals create power differentials and the attitudes of vendors lead to feelings of vulnerability and unfair treatment among consumers. The lack of accessibility of the built environment leads to a restriction of human rights with respect to access to the environment and restricts independence. All the barriers restrict opportunity for independent living (social participation) for individuals if they cannot obtain the assistive technology that they require. Inequality is maintained, not just by the inequitable distribution system, but also by biases in the attitudes of professionals, vendors and members of society at large.

Respondents primarily discussed barriers in their present living situations. However, some respondents proposed solutions for changing the system which were classified as facilitators for the future. Suggestions to facilitate change included consumer recommendations involving: changes to the government sponsored programs, changes in attitudes of professionals and vendors, and recommendations for a government funded Product (Assistive Technology) Display Centre. Recommendations for change also emphasized the need for providers to recognize the need for peer supports, to move away from the medical definition of need and adopt a definition of need for assistive technology consistent with the principles of independent living.

Comparison of these findings to the Whiteneck & Fougere (1996) model have also been presented. Using this framework, the researcher has concluded that the delivery of assistive technology presents several handicapping situations for the person with a disability. Mechanisms for overcoming barriers suggested by the participants were also presented.

In the short term, the respondents have created strategies to overcome the barriers. These strategies will be discussed in Chapter 7: Strategies for Acquiring Assistive Technologies Needed for Independence.

Table 4

**Intervening Conditions: Barriers and Facilitators
to Acquiring Assistive Technology**

Intervening Conditions	Present Barriers	Impact of Barriers on Consumers	Suggested Facilitators
Information Sources	<ul style="list-style-type: none"> - 3 groups lack information - transportation difficulties - no display centre - magazines offer only a little - people don't know where to get info - people still want human contact - don't know what's available from Home Care 	<ul style="list-style-type: none"> - lack of informed choice 	<ul style="list-style-type: none"> - more access to info - locate vendors in malls - sell assistive technology through regular stores - Assistive Technology Display Centre - recognition of peer supports
Cost/Eligibility Requirements	<ul style="list-style-type: none"> - inflated prices - vast majority not covered by Govt programs - eligibility limited by: <ul style="list-style-type: none"> - type of disability - cause of disability - medical need - vocational need 	<ul style="list-style-type: none"> - lack of choice - inequitable distribution - lack of rights 	<p>Cost:</p> <ul style="list-style-type: none"> - refundable through taxes <p>Eligibility:</p> <ul style="list-style-type: none"> - determine by independent living needs - panel of gatekeepers
Bureaucracy	<ul style="list-style-type: none"> - lack of coordination across multiple bureaucracies - needless contacts by professionals - time delays - inflexibility 	<ul style="list-style-type: none"> - consumers do without rather than going through bureaucracy - power differential - limitation of risk and responsibility to consumer 	<ul style="list-style-type: none"> - decrease layers of bureaucracy - increase informed choice - separate assessors from the gatekeepers - transfer more risk and responsibility to consumer - transfer of power - Assistive Technology Display Centre

<p>Choice</p>	<ul style="list-style-type: none"> - depends on income - depends on cause of disability - dependent on employment/vocational eligibility - limited by type of disability - only one type of wheelchair available in government program - can have same wheelchair for several years - limited selection from Home Care - limited by bureaucracy 	<ul style="list-style-type: none"> - limits what is available to consumers - lack of independence if unable to have necessary equipment - lack of independence if unable to have necessary equipment 	<ul style="list-style-type: none"> - Assistive Technology Display Centre - Mesh government and private sector and give consumer money to purchase equipment - consumer pay for part of maintenance - set up arrangement with vendors to do repairs and government pay for
<p>Professionals (Occupational Therapists)</p>	<p>To Consumers:</p> <ul style="list-style-type: none"> - lack of autonomy - lack of choice - lack of flexibility - lack of partnerships - lack of respect for diversity 	<ul style="list-style-type: none"> - power differential 	<ul style="list-style-type: none"> - recognize consumers as experts - change professional attitudes - relationships between consumers-professionals as two-way - professionals give up control and power - increase flexibility of service - Assistive Technology Display Centre
<p>Vendors</p>	<ul style="list-style-type: none"> - push the sale - not consumer orientated 	<ul style="list-style-type: none"> - vulnerability - unfair treatment 	<ul style="list-style-type: none"> - unbiased assessor/advisor (OT, CPA Counsellor) - Education of Consumers in dealing with vendors - Assistive Technology Display Centre
<p>Built Environment</p>	<p>Outdoor:</p> <ul style="list-style-type: none"> - inaccessible entrances to buildings, sidewalks - hazards/climate <p>Indoor</p> <ul style="list-style-type: none"> - inaccessible apartments - Attitudes 	<ul style="list-style-type: none"> - lack of human rights - lack of independence if unable to use necessary equipment 	<ul style="list-style-type: none"> - Need to change public and designer's attitudes - enforce laws on accessibility

CHAPTER 7 - RESULTS: STRATEGIES FOR ACQUIRING ASSISTIVE TECHNOLOGIES NEEDED FOR INDEPENDENCE

“Strategies for acquiring the assistive technology needed for independence” equate to “action/interaction” in terms of the Strauss and Corbin (1990) **Paradigm Model** and are defined as "strategies devised to manage, handle, carry out, respond to a phenomenon under a specific set of perceived conditions" (p.104).

In the previous chapter, intervening conditions that presented barriers to getting assistive technology included cost, eligibility regulations, lack of information, lack of choice, complicated bureaucratic process, negative relationships with vendors and professionals and lack of environmental accessibility. These barriers in turn create a handicap situation as suggested in the Whiteneck & Fougeyrollas (1996) model. Since acquiring assistive technology is vital in achieving and maintaining independence, participants discussed the following strategies for overcoming some of these barriers:

- 1) Playing the Game
- 2) Peer Support
- 3) Development of Resource Networks
- 4) Speaking-Up
- 5) Invention of Assistive Technology

These five themes or “strategies” were extracted by the researcher through analysis of the data. Relationships of these themes to barriers were constructed by the researcher and not defined by the participants. These strategies are numbered for convenience, not by priority.

Playing the Game

Several respondents talked about the strategy of “playing the game” to get the equipment that they needed. It was interesting that this terminology, “playing the game,” came up independently in several interviews. “Playing the game” seems to mean going along with a professional’s particular agenda first in order to meet the consumer’s ultimate needs.

In the first example, the consumer had gone to the occupational therapist with a clear idea of what she wanted. Instead of dealing with the consumer’s main concerns, the consumer felt that the occupational therapist had her own agenda. She stated:

“..... I didn't have a foot stool, or foot piles [foot rests] because I found they always got in the way, so my legs were hanging and she said, you really shouldn't be doing that it's not good for your back... Initially it was like, you're in a wheelchair, you should have foot rests, you should have this, you should do that, and we have to try this and it's like [I thought]- oh no, I don't have time for this.... I looked down and thought I'm here for my butt, but she realized then that I knew what I was talking about and re-tracked and said, “okay we'll try these things and we can see what we can work out”. I took into account that I felt that she's probably just young and very ambitious so all these things that were wrong and didn't really look at me living independently and this is my issue.... This is my need, let's just do that, and so that part was good, once we got through the game” (001.II. p.5).

As is turned out, the respondent did later listen to some of the suggestions offered by the occupational therapist and found them to be helpful. However, the main point of the narrative was that the therapist was not listening to the respondent’s main concern at the time of the encounter. Though the occupational therapist was probably clinically correct in focusing on these other areas of concern, it was her approach that the

respondent did not find satisfactory.

In the next example of a respondent's narrative (which was previously cited as an example of the power of professionals), the respondent knew what he needed to enable him to drive safely. However when he was advised by the therapist not to drive without the cushion prescribed, he "went along with it" or "played the game" to facilitate the process of obtaining his license. His solution was to throw the cushion away as soon as he started driving.

"I think I was probably a little intimidated, like I say the power to grant you these devices or to certify that you get a license is absolutely not your own - it's absolutely vested in the people and there is a system of trust and collegiality of the various actors....Because they work together a lot on these things and they vest their confidence and credibility in each other, it's a little network of people, and so they all are part of the gang. If you get somebody's nose out of joint you're not going to - doesn't improve your chances of getting that license. So if an O.T. tells me I need a cushion behind my back, I don't think I do, I wonder if it isn't dangerous but if she's strong enough on it I'll probably go along to try to move the process along and then throw it away later when I confirm in fact that it's a risky thing for me." (0012.IL p. 8)

Even though this individual is considered to be an active leader in the Independent Living movement, his statement suggests that he still felt powerless in this situation. He felt he had to "go along with" the therapist's ideas or "play the game" in order to move the process along. There seems to be a difference between the macro-power that persons in advocacy roles have and the micro-power that they have in dealing with professionals. Other respondents also mentioned the fear of getting professionals' "noses out of joint" and thus not getting what they needed. The presence of a power differential between the

professionals and the respondents/consumers seemed evident.

One consumer articulated how she was able to "get out of "the game" by having the ability to purchase some of her own equipment as well as becoming more assertive in her interactions with providers.

*I think I've become much more assertive through the years. I really feel now that if I'm buying something, there's no reason why somebody from Everest & Jennings can't come to my house and show me the catalogues and go through stuff with me and I would demand that kind of stuff now, where a few years back I wouldn't have - I would have left it up to somebody else to do. So my attitude has really changed quite a bit, and that makes a difference... sooner or later I think you take on that kind of maturity anyway - .enough is enough..... if I want this I go down and get it, you just forget about **playing the games** after a while I think (009.IL p4).*

Thus "playing the game" or going along with the professional's agenda to get the desired equipment was an important consumer strategy for overcoming the barriers inherent in the attitudes of professionals and bureaucratic structures. This strategy seems to be "if you can't beat them, join them", at least until the respondents get what they want. Another strategy described by respondents involved obtaining peer support as a way of gaining more information.

Peer Support

When it comes to finding out about assistive technology, talking with peers and seeing them use equipment seemed to be a very important information source. Peer support seems to be used to gain what the respondents perceived as the "best" information as opposed to the perceived non-experienced view of professionals. Peer support also

enabled them to gain information when the individual does not know other sources, to avoid red tape, and to gain a non-biased viewpoint. Both formal and informal approaches to using peer support were identified in the data obtained from informants.

An informal approach occurred whenever the informant either knew someone and asked that person for advice or saw someone they did not know (perhaps in a mall) using equipment such as a wheelchair, and then asked that person about their experience with the technology.

A more formal method of peer support is offered by persons with disabilities who work for a disability-related organization and whose job it is to offer advice on assistive technology. In Winnipeg, more formal peer advice on technology is provided by the rehabilitation counsellors at the Canadian Paraplegic Association, the information and referral workers at the Independent Living Resource Centre, and people employed at Ten Ten Sinclair. Although classified as a more formal mechanism for peer support by this researcher, advice was provided by these programs without charge and without the formal structure of referrals and professional consultation. There are no prescribed procedures to go through to receive this advice. For many people, these formal peer advice sources would be the first people/places that they would think of contacting. One reason is that these individuals and programs have become well known in the disability community over the years.

Informal Peer Support: “One Quad tells another Quad”

Respondents described informal peer encounters which enabled them to obtain

information on equipment.

Interviewer: How do you find out information about the equipment you need?

Well I'm on the chapter of the Spinal Cord Society, we've got a pretty strong membership. So one quad tells another quad things that work really well (013.NIL p2).

I bumped into a guy who had one of these wheelchairs and he told me he got it at [Vendor]. (013.NIL p4)

A guy named " _____ " used a small teapot that you could buy at Beaver Lumber, small glass teapot you could make tea in. At that time I had strength so I could lift a teapot, it held about 2 cups of tea so I could make a cup of tea for myself (006.NIL p 6).

On the side of my wheelchair I have three different little bags hanging on the side of my wheelchair that I carry different things in - I have another set of keys, the door opener that I use to get in and out of the building - I carry that in one of them and the idea of these bags - that came about from one of the other patients in the hospital. Many of the patients in the hospital [referring to a long term care facility where the "patients" have lived for several decades] have these bags inside the chair where they carry different things that they want to have with them when they're traveling through the tunnels and whenever they go outside (006.NIL p7).

Thus individuals either actively sought out advice from peers or serendipitously found out about equipment by observing another person using some type of assistive technology.

Some of the equipment was invented or purchased as mainstream products by the peers.

Formal Peer Support: Peers with Disabilities Who Are Paid to Offer Advice

Some respondents discussed how they would call a disability-related organization for advice.

I've got hundreds of things from CPA [Canadian Paraplegic Association] and I've also got hundreds of ideas from CPA and also I've got much help from CPA and by phoning up they would tell me who to phone or where to go or where I could try to get this or that, and that's just CPA and I think ILRC [Independent Living Resource Centre] is right up there with CPA, I just haven't used them as much because they're a new organization (006.NIL p 7).

Included in this study were respondents who were formal peer counselors and who provided a personal as well as a vocational perspective. They had a dual role in the study: one speaking as a consumer and one speaking as a paid peer counselor.

Several important points arise in the following narrative. The first suggests that although there are various other information sources, people seem to want to get information from peer counsellors. The second point is that a peer counsellor with a disability-related organization is not affiliated with commercial vendors nor with rehabilitation professionals; therefore he/she offered a relatively non-biased view of products to the respondent, compared to advice provided by vendors. Another important point raised by the informants focused on how consumers come to know about formal peer counselling and counselling services offered by disability organizations.

I do get a lot of calls here at the office. I had one this morning from a former tenant of ours that was looking at putting a lift and stuff in his vehicle and phoned me up wanting to know suggestions and advice where to and would it be appropriate to do a mini van and give him a cost of the equipment. Is it practical or should he be looking at something else? I mean that kind of information is

more like a peer counseling or peer information giving I suppose from experience, as opposed to his going out into the market place. In the private sector you're sort of at the mercy of the salesman. If you go in ahead of time with some information from somebody else you're usually okay. I'm not saying all salesmen are bad, they're probably not, but, some salesmen are more salesmen oriented than product for you oriented. I don't know, I mean there's places where people can get information from if they're aware, ProductAbility for example, the ARCOR [Aging Product and Research Centre which closed down since this interview] building for another one provides a lot of information. There's the [---] OT. Department, which probably has a large wealth of information and there's all the variety of disability organizations around that have some knowledge of the equipment. Usually they have somebody on staff that's knowledgeable but whether or not all consumers know that, I don't know (002.IL p.5).

Reasons Why Individuals Seek Information From a Peer Counsellor

The following statements by respondents describe the reasons consumers preferred to get information from a peer counsellor.

Having that individual [Referring to a CPA counsellor] in your arena or with you when you have the stuff done, you usually end up with the equipment you need (002.IL p4).

I don't know, the sense that I have is there is limited amount of information available, but the best information is you call up people who use the equipment and they will provide you with information (007.IL p.7).

The key word is that the respondents felt that the “best” information comes from someone who uses the equipment. Vendors should be cognisant of this fact when it comes to marketing their products. Professionals need also to be aware of the credibility of peer advice when providing prescriptive advice. The following narrative demonstrates how heavily weighted the opinion of a peer is.

As far as private sort of vendors, I purchased a lift for my van from a private vendor, and it was an alright experience as well. I didn't really hunt around - sort of like one vendor and kind of whatever he said I just sort of accepted. Everybody, peers told me this vendor is a good guy and pretty knowledgeable in what he was doing so I just sort of went with that. I don't know whether there would have been other places to shop around I didn't try very hard, I just went to the vendor that was recommended to me. The only fact that it was kind of expensive but it was an okay experience as well (004.II p.2-3).

This experience is probably not too different from what happens in the mainstream marketplace. For instance, if someone is going to buy a computer, he or she often talks to peers who already have a computer and asks them where they made their purchase before making a decision.

Although respondents seemed to value this peer interaction highly, it is uncertain whether professionals acknowledge the process as a valid method of obtaining information. Respondents described situations where they were given a list of products or a list of vendors when the time came for professionals to discuss assistive technology needs. However informants did not mention that they were provided with lists of disability organizations providing peer counselling.

There was some suggestion that peer counselling may even be discouraged by professionals. One respondent who is a formal peer counsellor working in a large rehabilitation facility, described how the occupational therapists there did not utilize his expertise in the area of assistive technology.

There seems to be a growing I don't know if it's animosity but there's a growing territoriality, like you're stepping on my bounds... I know that in prescribing wheelchairs, we have the vendor come out and bring his little booklet of wheelchairs sort of thing, and we would go over the various options on the chair and I would say, you have to remember this, that and the other thing, and knowing what it's like to transfer or to get around in a wheelchair, I'm more aware of some of the obstacles that a person can face and how some of those obstacles might be better overcome given something as simple as fixed foot rests as opposed to swing away foot rests or that type of thing, yet what I was finding was that by the time we got together with the vendor and the client, the occupational therapist who had already made up their mind as to what they should order, so it was just a matter of rubber stamping it and I would ask them, "why aren't you looking at this option or this option? If you look at this option it's going to allow a person to do this, that and the other things" and that was almost like: "you're challenging my professionalism" or something (017.IL p.4).

This respondent's statement demonstrates how the professionals did not treat him as a colleague or a member of the assistive technology team. It also raises questions about the meaning of "expertise" and "professionalism". Is a peer counselor seen as a professional by consumers and also by rehabilitation professionals? Who is perceived as having the right amount or type of expertise?

The following narrative illustrates how peer support differs from other information sources and how peer support could be expanded and encouraged by professionals and others interested in this area.

The relationships that are developed are not in the traditional sort of philanthropic mode, but much more of an egalitarian mode and I look on that quite favorably. I think people with disabilities need to be more sharing and empowering of each other in terms of solutions and technical aids, device solutions, and resources that there are not only always in the public domain or in the private sector domain as it exists but also the voluntary end peer support kind of domain. There are many things that I have seen other people with disabilities use or do that has benefitted me

and I'd like to think that sometimes when I find it works it will help somebody else as well, so we've got those areas to explore and consumers are ideally situated to do it. I also think that various professions, other interested parties to the whole assistive device area have a role to play in supporting sort of explorations in these areas, development of these areas (012.IL p.20).

One approach suggested would be a combination of the expertise of peer counselors and professionals. Many of those interviewed advocated the need for an information and display centre for assistive technology, which would be staffed both by persons with disabilities and professionals.

Resource Network

Another strategy to get equipment that seemed to be very important to a number of respondents was that of developing “contacts” or a “resource network” (010.NIL, 008.NIL, 006.NIL). Having a resource network means knowing whom to contact when assistive technology needs arise. From the perspective of overcoming barriers, it also means that the individual will have control over who is contacted and in what time frame equipment is obtained, rather than having to rely on professionals and waiting lists. The use of a resource network also facilitates access to equipment which is not available from the usual sources or finding lower cost solutions.

From the data, it seems that resource networks take time to build and each person has his/her own list of contacts. Several different “contacts” could compose one individual’s resource network including specific professionals, specific vendors, upholstering companies, disability agencies, people who will fix a wheelchair in a crisis and

peers, to name a few.

The following paragraph is one person's description about how a resource network is built.

*So you have to have your **resource network** - one will do this, one will do that, but you don't get that overnight, you develop this..... Just by being around for years mostly. You have rapport with the people you worked with out of the Rehab or at the Society wheelchair department, or this or that. You go to these conferences like the one that ILRC put on not so long ago, you scout around and you get leads and you take names down and keep track of it or you want something - you phone and still can't find it, you go back to ILRC or something like that and you see what other information they have or the CPA which also has a good resource for information. It's just - you just build it up. **There's no magic way of doing it, it's basically contacts, it's talk to people, have them talk to you and share information** (010.NIL p.6).*

This same respondent described how his own resource network worked in his research to find an appropriate and cost-effective lift.

I have a Hoyer lift that we borrowed from the government. They didn't have the bath sling that was suitable for me, it wasn't big enough to sit comfortably, so I just phoned around to the suppliers of the bigger swings, Stevens or whatever it was, one of these medical suppliers and I ordered a bigger bath sling, because I couldn't function in the other one. Home Care didn't have one, they had no intention of buying one, so I augmented with Worker's Comp, filled in the blank. The reason why I should have a Hoyer from Home Care Equipment Pool was because they have a service department that come and check it once a year, where Worker's Comp have nothing like that - they have no service people that handle these things, so you can't really get it serviced properly (010.NIL p.4-5).

In this case the individual was stuck because he needed the Hoyer lift and had to rely on Home Care because they are the only provider that will service the device.

However, they do not have adequate adaptations to meet his needs. He had to use two of his contacts - a vendor and Workers' Compensation - to supplement the device provided by Home Care. Thus one reason that a resource network was required was because the necessary equipment or adaptations to that equipment were not available from vendors and public providers such as Home Care. This individual had to take the initiative to make contacts to get the right type of equipment for himself. His narrative implies, that the professionals involved from the Home Care program were not doing the "leg work" for him. The consumer was therefore forced to do this by himself.

A resource network is necessary to provide the individual with some control over assistive technology choices. This is illustrated in the following passage.

You can't let life pass you by and not take control yourself, otherwise you have someone else make decisions for you. They'll [professionals] pick whatever they feel works, might be fine, but they haven't got your concern in mind, and the end of result will be - have somebody do an adaptation for me that won't be up to spec for what I really need. So you really have to do that (010.NIL p.8).

Another person spoke of making contacts when he served on various disability-related committees which later assisted him (006.NIL p14). Yet another respondent discussed how being part of a network for a long time and getting to know specific therapists or people at rehabilitation engineering had allowed him to obtain items more readily from the system. Long term involvement also allowed people like him to build their "resource network" (008.NIL p.3).

The respondents' narratives emphasize that building a resource network requires a combination of time and effort. Effort is very important because they perceive that it takes a certain amount of motivation and assertiveness to seek out required information. As one respondent explained, *"I think the people who are willing to go and dig like me and [Names of peers] we'll find what we need somehow or other. If we can't we'll describe to somebody what we want and get it made"* (008.NIL p.10).

This idea of being assertive to get what is needed is an important sub-theme of building resource networks. Without this ability, a network would likely not be built. This assertiveness or "speaking up" will now be discussed.

Speaking-Up

The ability to be assertive enough to get the equipment that is required seems to be another important strategy described by several of the respondents (003.IL, 009.IL, 006.NIL, 017.NIL). One respondent felt he was lucky to have been born an assertive individual and that his work allowed dealings with various bureaucracies which has assisted him in this area (003.IL p4). There appears to be a fine line between being assertive and being "obnoxious", that respondents stated that they had to be careful of.

They're all people who put in a day's work and they try to be helpful and they're helping a lot of people, it's just the system. Makes it impervious to a lot of people because there's just so much you can do and so many hours in a day and so on, so unless you know how to keep your needs up front without being really obstructive to other people ... You either end up getting so obnoxious that they avoid you like you're a plague or you become so subservient you also don't get dealt with. It's tough out there because there's only limited resources. There's more need than there's

resource and there's a lot of people in my position (017.NIL p. 9).

This same individual described his approach to the “art” of being assertive without being obnoxious.

People in the system, for the most part, seem to be willing to work with me and if possible they do it. They go out of their way, they make the extra effort themselves and I have some idea of why it works well for me and not for others. I try to learn the system and make demands on it at times that are least disruptive and stuff like that. I also try to make it humane. I had a bus driver once who got injured in an accident and I sent him a get well card and you know that guy forever and ever is always prepared to go out of the way for me now because I treated him like he was a person . No big deal, but a lot of handicapped people are absorbed with themselves and with their own problems and they don't do that, they don't look outside themselves, they're very very demanding (017.NIL p 5).

Both the building of a resource network and speaking up in articulating wants and needs requires a certain amount of motivation and assertiveness. What happens to consumers who do not possess these abilities? Two of the respondents discussed their situations where technology users were not assertive.

You're always going to have disabled people that are not going to have what they need and some of them are living in bad situations where they can't get into their bathrooms because their wheelchair is too wide, but they don't have the determination to get (.....) to fix that or somebody to fix the doorway or get some kind of group to fight for them or to move to a different apartment or - so they call staff to carry them into the bathroom and carry them out of the bathroom. You're always going to have people whether they're in wheelchairs, disabled, walking, old - you have old people out there right now that aren't living very well but they just don't have the will to fight to make their life a little better (006.NIL p.13) .

Another respondent who works at a disability organization stated:

I run across people who can express it and see that they haven't got a modified computer they'll tell us - vision handicapped people that don't have various lap top computers and things. Or physically handicapped folks that are just getting by because that's the way it is and wish they had a counter top they could reach or a can opener they could work or a power chair when they struggle with pushing it and either they psychologically they got turned down many years ago therefore they assume they'll always be turned down. Or, other kinds of needs that people don't often discuss. Some people do get angry and use the anger technique to get out others over resign and accept the fact.... amazing stories of people who just can't reach the jars or reach the stove and they accept it, that's the way it is, and they're frustrated but feel they can't do much about it. It's therefore accept a lower functioning life style and it is their lifestyle, partly because they may lack creativity in devices themselves or how to motivate a neighbour to design something or even lack the confidence to negotiate (003.II p13)

These two passages are important because these respondents provide some possible explanations about why some people do not get their equipment needs met. The possible explanations, as they described them, include: their unwillingness to fight; their previous rejection which has left them feeling that they will be turned down again; their discomfort at discussing certain issues; their acceptance of the situation; their lack of creativity; their inability to motivate others to assist them; and finally their lack of confidence in their own ability to negotiate.

The diminished quality of life described for non-assertive individuals is alarming because individual adaptation could change if appropriate resources were made available. This raises many questions such as: What percentage of people with disabilities are in this situation? Why haven't these individuals learned to be assertive or built up a resource network? What are the abilities necessary to do this? These are all questions that could be investigated in future research.

Conclusions: Resource Networks and Speaking-Up

In conclusion, the narratives emphasize that building a resource network and speaking up for one's needs are very important strategies in obtaining assistive technologies. This researcher feels that more respondents would have discussed these themes if they had been more systematically probed. However, these themes were only identified during the data analysis and the researcher did not make follow-up interviews. This points to an interesting area for further study. It also would be interesting to expand on this dimension and compare individuals' resource networks.

Invention

Another way of getting equipment that was described by respondents was to invent it. Many respondents described experiences involving invention of technology. Technology inventions ranged from simple low-tech solutions like using a hanger to pick up items from the floor to very complex vehicle modifications. Many times the respondent had the idea and had to seek out either an "off the shelf" solution or seek technical expertise to develop the invention. In some cases, the invention strategy helped overcome the barrier of cost. A list of reasons why invention occurs includes a) cost motivation; b) a unique situation with no commercial solution available; and c) consumer needs for modifications to existing equipment made by Rehabilitation Engineering.

Cost Motivation

In the first case regarding cost motivation, the individual had pain in her gluteal region from sitting in the wheelchair. A professional had advised her to purchase a pressure relief cushion called a “Jay Cushion”. However, she felt she could not afford one.

Thinking I can't afford \$450 just to sit on, there's no way I can afford this, so then I started thinking about I really only need the gel for one small area and so I said, can we look at buying a gel refill pack and you can buy little packs that they use supplemental packs and it's about 8" long and about 3" wide and it was twenty bucks. Now that's in my budget, I can afford 20 bucks and I thought, if we had that right in the area where I sit then the rest of the cushion would be fine. So I went back to Rehab Engineering and said, this is what I want to do. Can we cut a hole in the solid foam that you've given me and insert this gel pack so that the part that I sit on has the gel so it moves constantly, the pressure's always solid all around but still very soft in that spot. So they said, sure, let's try it. So I bought the gel supplement, paid my \$20, went back to Rehab Engineering, we took the cushion apart, cut out the hole specifically for that one spot, crunched up the gel pack, put it in and it's been working fine. So you sit there and think something that could have cost me 4 or 500 dollars cost me 20 dollars and a little bit of creativity is working just fine (001.II., p5).

A more high-tech situation is illustrated in the following narrative of a respondent who wanted to have an overhead track system installed to lift him from bed to wheelchair. The provincial Home Care program would supply a Hoyer Lift, but this device has several disadvantages which are overcome by the newer track systems. One main disadvantage is the floor space required for the Hoyer Lift. The respondent's only means of acquisition was to purchase the overhead track system. However, when he learned that it would cost

over \$6000, he decided that he could not afford it. The respondent describes the process of developing an alternative, more cost effective system.

A friend of mine came up with the idea and he found out that you go to Beaver Lumber and for \$20 each for these tracks we bolted them through the joists, wired them and chained them... They're used for garage doors and gates on farms. Big sliding farm doors... Mine's made of chain, a chain pull like you use to lift car motors - chain pull, but it works beautifully.... And it's dependable. I never have to worry about parts. In the summer I take the chain out to my boat in the Lake of the Woods and it gets me onto the top deck. I built a steel arm up there, bolted it to the floor and supported it and just put my chain pull there and it lifts me up from the bottom deck (013.NIL p.5-6).

In this case, the solution not only assisted the respondent with his self-care, it also provided a way for him to enjoy a leisure activity he had been involved in prior to his accident.

A Unique Situation With No Commercial Solution Available

Several individuals developed innovative solutions out of necessity, mainly because they were not aware of a commercially available alternative. One person described his approach:

I have an opening in my pant leg made with Velcro so I can go to the bathroom myself...rather than a regular urinal, which is big and awkward and heavy, I have [detergent bottle] urinals that are about half the size and much narrower...and I cut the top off them and then put a string through so it's like a handle on the top and then I can put this detergent bottle in between my legs and go pee....So an opening in the pant leg is - it only works for males though (006.II p.3).

In this case the respondent developed a solution not only to increase his independence but

also to accommodate the other “assistive technology” that he was using - a back brace.

This same person developed an idea to modify his laptray with a shelf to accommodate carrying personal items.

I have a lap board that has a tray underneath. It's invisible, nobody knows it's underneath there. I can reach underneath the edge of my board and slide a door open and in that drawer I have my keys and deck of cards and important things you know, things I carry with me, money. You don't want to carry them out in the open or in your pocket where people can grab it (006.IL p.6)

In the next case, the individual could no longer use his van because of changes in his functional ability. He needed to wheel his chair up to the steering column to drive the vehicle. This meant that the floor of the van had to be lowered. However, his wheelchair was three inches too wide. He continued to analyse the situation and devised a way to lift himself into the car seat. In this case he sought out technical help from someone in industry and brought these ideas to Rehabilitation Engineering.

I am working on a new idea of modifying my current van in terms of establishing some kind of a system that can help me transfer mechanically. We had some real problems with people from Rehab Engineering and they really were not enthusiastic about any kind of lifting mechanism. We're working conceptually trying to solve problems and I became very friendly with someone who happens to be in a metal fabricating business, and he's a very creative person and actually he had some ideas which we shared with Rehab Engineering and now we have a plan. This friend of mine is working with the Rehab Engineering people and he will in fact in his factory fabricate certain things. It seems the engineers are satisfied with the idea and in the end my chair might be modified along with the van and we'll have not a lifting device but a sliding device created interactive between my chair and the car chair. The people work on that, but it's a long process and we just recently had a meeting where together with rehab engineers and technicians with this other fellow and started thinking through the ideas and planning step by step so it's a long process, so I

again there's a lot of frustration - the costs for anything are unbelievable (017.NIL p3,4).

This consumer's account describes how he was able to bring together expertise of people working in industry and rehabilitation engineering to create a technical solution initiated by him. The respondent obviously had to persevere in advocating the modifications in the face of Rehabilitation Engineering's reluctance to accept his original idea.

In the following example, the individual had to turn to family and friends for assistance in building a home-elevator system.

If you're looking at the small elevators as a technical aid there's another area that I definitely had a lot of problems with because the house I lived in with my parents 15 years ago, we wanted to build an elevator to go into the basement and there were great complications again. I got my brother-in-law who was an electrician to basically build a lift that goes into the basement rather than going through the standard process. I phoned up this person and that person and it always seemed to be very complicated. You try to get a lift that would go into the basement and it was a simple thing for him and his friends to hook up a make shift elevator with a winch and a hoist on it and a couple of cables and the box car with some angle iron - irons in the corner that go up and down and you just put a platform on it. So in that area a lot of the things that I found, except for the wheelchair, [are] things that my friends or my family around me would provide solutions. That has worked out well (007.IL p.6).

The Need for Modifications to Existing Equipment made by Rehabilitation Engineering

Another reason that items were invented was to modify technology produced by Rehabilitation Engineering. One respondent stated that he received the item and, after trying it, found that it did not suit his needs. He therefore requested that Rehabilitation Engineering modify the technology to fit his living requirements.

Like this lap board, it's basically a fourth generation lap board, finally refined it to the point where I have the piece I need what I have now. I originally had a monstrosity that was an extra eight inches and was wide, I couldn't turn corners, I couldn't get through doorways. This sort of is neat enough looking - I don't mind even going to a bar, where before I'd hardly go to a bar with it, let's put it this way, it was ugly. But they [Rehab Engineering] didn't care, they wanted to make sure it was functional, they weren't thinking of cosmetic, they weren't thinking of that at all, but you had to adapt that yourself. Next time you had something worked on, you say okay, that was great, but let's do this and this and this and make it look better that way I can lean over and see my feet. See whether my leg bag is full or isn't which is very crucial and all those little things that look normal or looked like they are there, they're all there for a purpose but they're to show. That's because you have to think before you get something done, but you can't do it immediately, you haven't - you have to put some experience behind you and trial and error. That's the only way you can get to the end result that works. As far as Rehab went, they tried (010.NIL p.3).

His narrative provides an example of a situation where the device produced was functional but did not have the cosmetic appeal for the consumer. In the case of the lapboard, the modifications were also not functional because the device obstructed the individual's ability to see his leg bag used for collecting urine. This same individual described another situation in which invention was required to modify a device made by Rehabilitation Engineering.

I had many gadgets made: spoons and forks with a loop just out of cheap aluminum material which discolored. It looks terrible, you go eat in a restaurant and it's really not pleasant to look at. I feel it isn't. So I decided to make it look right. I got on the phone, I phoned around and I found a little metal works - they sold me Stainless Steel metal with the certain thickness that I needed, I had it cut the right width that I needed for the loop, went to the Rehab and they had a department there at that point and I showed them another fork I had that was just perfect and said, I want it just like that but with Stainless Steel which I supplied with the rivets - they didn't have that either. I supplied the supplies and I found somebody to do it because I had good rapport with the people there but

good rapport helps. It opens doors (010.NIL p. 4-5).

This respondent describes the trial-and-error process that both the consumer and Rehabilitation Engineering go through in the development of a piece of assistive technology.

From this case and previous examples, it would seem that there is an onus on the consumer to seek out alternative solutions to a problem. As this respondent stated, "you must take control" (.001NIL). The obvious question is, how does someone with a disability become an inventor and a seeker of alternatives? The process of seeking out information, conceptualizing a device and finally communicating the ideas to someone to fabricate it, takes a great deal of skill. Some clues to this process were articulated in the following narratives.

*I'm very interested in technical aids and I'm very interested in gizmos and gadgets as they say - because I feel I have the **mechanical mind** I like thinking of how to solve the issues so that it's not going to cost a million dollars, and that it's something that could be made at home. I really like to see how people can create their own - I mean before I had a reacher, I would be picking up clothes and stuff from the floor with a hanger. I would just take a hanger, the wire one, straighten it out as far as, instead of having the part that you hang the clothes on, I would just pull that straight so there was a hook at the end, and I could pick up stuff. If I needed to pick up paper, I would put a piece of tape on the bottom and I would still pick up paper. So you know it's that ingenuity that started me thinking there's gotta be better ways and so when I'm buying equipment now, like kitchen supplies and stuff, I really try to see like can I lift it, can I work it myself because that's my goal (001.NIL p. 7).*

Another respondent stated:

You find ways, you have to think. I was in the hospital for 15 months, right? I was drinking by a straw all this time. I went through O.T., I made

a checkerboard, I did a few other odds and ends, my heart wasn't in it because it was the stupid stuff I had to do, it just wasn't progressive for what I needed. I come home and we had the old coffee mug, glass, and I discovered, hey it's just the right size I actually picked up half a cup of coffee by myself. By that time I was so tired of drinking from straws anything was better, right? So that was my first discovery as far as I know. Now I stayed with cups, searched high and low for a thermal cup that wouldn't get hot when I drink hot fluids and try to make it work. When you get something that really works, you buy a batch, make sure you don't run out and have an adaptation made if you need to, and go from there. You have to do the research, you have to have the idea of what you need and say, look I need a filler here because it won't fit and that doesn't need an O.T. to tell me that, they'll do that if they have time for it. So that's basically how it has gone. You have to be alert all the time and aware (010.NIL p. 9).

One individual described an elaborate model that he built to convey to rehabilitation engineering what he wanted.

I particularly had worked closely with them [Rehab Engineering] over the years to design products for all my needs. I often would build and design a prototype and bring it in and show them and I remember once building a prototype extendable ramp on a Meccano set and showing them how I wanted the leverage to work and the spring-loaded system to work and they basically took that model and built it into the very extendable spring-loaded ramp I have now which allows a person with my weakness to raise and lower a 500-pound ramp with the spring-loaded system and leverage. That relationship with them was very healthy. I used to make gadgets myself before I had polio and so natural luck and interested in devices and leverage and spatial things (003.IL p.4).

The following comment by one of the respondents implies that only certain people participate in this process of seeking out alternative sources and developing new ideas for modifying their own devices.

I think the people that are willing to go and dig, like me and [others], we'll find what we need somehow or other. If we can't, we'll find somebody

to whom we describe what we want and get it made (008NIL p.10).

Conclusions: Invention Strategies

The invention of assistive technology is another important strategy used by some people with disabilities. The need for invention of technology occurred for three reasons: cost motivation, a unique situation arose where an item was not commercially available, and finally required modifications to items produced by Rehab Engineering. One wonders what happens to those individuals who do not have the motivation or resources to invent. Why do they not become inventors? Perhaps this process of seeking alternatives, conveying ideas and negotiating with people who will make the product, could be learned. Perhaps these ideas could be taught initially when a person sees an occupational therapist and then progresses through consultation with an organization such as the Independent Living Resource Centre. This is an area which requires further exploration.

In all of these narratives, consumers did not express resentment in situations where they had to invent a device. Indeed, many seemed to experience a feeling of self-satisfaction and empowerment in situations where they were forced to develop a device that worked for them. One area of concern to the researcher is the safety of some of these inventions. However, this concern is somewhat diminished in light of the fact that there are very few safety standards in place for any of the manufactured assistive technologies.

Summary of the Strategies for “ Acquiring Assistive Technologies Needed for Independence”

To conclude this chapter, several strategies to acquire equipment have been identified in the respondents’ narratives. A summary of these strategies for overcoming barriers and possible rationales are summarized in Table 5 (p. 184): *Relationships Between Strategies and Barriers*. Possible rationales are suggested by the researcher. For instance, "playing the game" and peer support may expedite obtaining the needed equipment. Peer support may provide a non-biased viewpoint, avoid some of the “red tape” by eliminating the need for professional assessment, allow the person to get the “right” equipment and obtain basic information that cannot be found elsewhere. The development of a resource network may be used to avoid waiting lists, to take control of the situation, to get products not available from the usual sources and to reduce costs. Speaking up allows the person to get his/her needs met and to take control. Invention of technology enabled the consumers to save money, to produce something not commercially available, to make modifications to devices fabricated by Rehabilitation Engineering or take control of the situation.

There was an emphasis on the theme of "taking control". This strategy is also consistent with the emphasis on consumer control emphasized by Independent Living principles. The theme was emphasized in consumers’ descriptions of their strategies for developing resource networks, speaking-up and invention. “Playing the game”, on the other hand, seemed to imply losing control and putting up with power differentials. It did

not imply the collaborative model that would be expected in an Independent Living framework or in a client-centred occupational therapy framework.

Although all strategies and relationships require further study, “peer support” seems to be very significant. It exemplifies the philosophy of the Independent Living movement. As previously mentioned, it mirrors what often happens in society with mainstream goods. The Independent Living movement has long advocated the use of peer counselling. This area of untapped resources should be formally recognized by professionals, policy makers and assistive technology researchers.

There is no direct evidence from these data that these strategies are used to overcome specific barriers, however, the researcher has extended the analysis to explore these potential connections based on the aggregation of data from the interviews. Further study is needed in this area.

Table 5

Relationships Between Strategies and Barriers

Strategy	Possible Barriers It Overcomes	Possible Rationale for Why it is used
Playing the Game	<ul style="list-style-type: none"> - Professional Attitudes - Bureaucracy - Power Differential 	<ul style="list-style-type: none"> -To expedite getting the equipment needed
Peer Support	<ul style="list-style-type: none"> - Professional Attitudes - Professionalization - Bureaucracy - Vendor attitudes - Lack of Information sources 	<ul style="list-style-type: none"> - To expedite getting equipment - To get non-biased viewpoint - To avoid red-tape - To get the "right" equipment - To get information
Resource Network	<ul style="list-style-type: none"> -Cost - Bureaucracy - Limited Equipment available - Lack of Information 	<ul style="list-style-type: none"> - Avoid waiting lists - To take control - Not available from usual sources - Cost saving
Speaking-Up	<ul style="list-style-type: none"> - Professional Attitudes - Bureaucracy - Limited Equipment available - Vendor Attitudes 	<ul style="list-style-type: none"> -To get "right" equipment - Keep your needs up-front - To take control
Invention	<ul style="list-style-type: none"> - Cost -Bureaucracy - Lack of Information - Limited equipment available 	<ul style="list-style-type: none"> - Cost saving - Not available commercially - Modifications needed to Rehab Engineer produced - Take Control

CHAPTER 8 - RESULTS: CONSEQUENCES

The final step in Strauss and Corbin's Paradigm Model (1990) is an analysis of the consequences arising from the interaction of features related to the core phenomenon. In this study, the core phenomenon is represented in "Acquiring Assistive Technology Needed for Independence". The mitigating features were organized under the previous chapter/categories of conditions, context, intervening conditions and strategies. The consequences related to the core phenomenon will be discussed in this chapter and will include the consequences of being unable to get assistive technology, the barriers in the present delivery of assistive technology and the strategies developed to overcome these barriers. Finally the consequences of differences in the experiences of those respondents highly involved or not highly involved in the Independent Living movement will be examined.

The Consequences of Not Acquiring Assistive Technology

If the core issue is acquiring assistive technology, what does it mean to the respondents not to have it? Not to have assistive technology means not to participate fully in society. It means the inability to work, to perform self-care tasks, and to participate in leisure activities. It means the individual cannot enjoy the technological advances that are available to other members of society. Not having assistive technology can also have important physiological implications. For instance, not having the proper wheelchair cushion can lead to the development of pressure sores which can result in weeks or

months off work or hospitalization. The psychological benefits of assistive technology are far-reaching. The technology enables persons with disabilities to participate in activities with other people, to get out of their homes and into the community, to contribute to the workforce and to have control over their lives. All of these benefits are lost to those who do not have assistive technology.

The Consequences of the Barriers in the Delivery of Assistive Technology

According to the data, the barriers in the delivery of assistive technology included the lack of information, cost and eligibility requirements, complicated bureaucracies, lack of choice, inadequate relationships with professionals and vendors, and the lack of accessibility of the built environment. These barriers seem to create general frustration, feelings of powerlessness, lack of control and the inability to take risks. In other words the barriers created a handicapping situation according to the Whiteneck & Fougeyrollas (1996) model.

The Consequences of the Strategies Developed to Overcome the Barriers in the Delivery of Assistive Technology

Some individuals have developed strategies to overcome these barriers. These strategies included "playing the game", getting peer support, developing resource networks, speaking up and inventing assistive technology. The consequence of these strategies is that the individuals may eventually get what they need. However, these

strategies take initiative, skills and time. Not all persons with disabilities know where to find formal peer support, are able to invent a device, or are assertive enough to speak up for themselves constantly. As a consequence, some respondents discussed how some individuals do without assistive technology.

The Consequences of the Respondents' Level of Involvement in the Independent Living Movement

In developing the original research design for this study, it was anticipated that the investigator could compare the experiences of the group of respondents who were highly involved in the Independent Living movement to those who were not. The qualitative sampling design was initially developed to select respondents with varying degrees of involvement in the Independent Living movement. Although the cohort was small, there were some differences in the experiences identified. For instance, regarding bureaucracy, those who were IL involved identified red-tape and the ambiguity and out-of-date approaches adopted by the system as barriers. These same people also identified barriers such as the impact of gate keepers and work-related or medical eligibility criteria. In contrast, the non-IL involved group identified long waits, not being believed and the intricacies of the steps necessary to obtain assistive technology. When cost was discussed, the IL involved group discussed cost in general as a problem for many people while the non-IL group discussed it more in relation to their own situation.

In general the respondents from the two groups articulated similar strategies for

obtaining technology. Both mentioned the importance of a resource network; neither group felt they knew what products existed in the marketplace nor how to obtain information about them. Both groups tended to get information from peers and from contacts in their resource networks. Differences in the responses of the two groups of respondents were observed. The IL-involved group emphasized the importance of speaking up, being assertive, and having visibility in the community. The non-IL group discussed this process more in terms of their being in the system for a long time, maintaining credibility and taking control of their own situations. Both groups discussed how they had to “play the game” in order to get the equipment they needed and both groups had invented their own devices. Both groups described mainly negative experiences in their interactions with professionals.

Although more people were employed in the IL-involved group than in the non-IL involved group, both groups lacked the type of equipment they felt they actually needed and in general neither group could afford to purchase the necessary equipment on their own.

In summary, the main differences were that the IL-involved group may be more visible in the community and more assertive. Therefore, they may be able to exercise more choice and receive technology more rapidly than individuals who utilized only the conventional referral systems. As well, they are able to see some of the issues more globally. However, many of those respondents who were originally classified as not having IL involvement had years of experience with the system and indicated that they were well known to resource people and were treated preferentially as well. The small

size of the two groups and spectrum of experience with consumer and rehabilitation agencies among respondents in both groups meant that it was difficult to draw definitive conclusions about the impact of experience with the Independent Living movement on consumers' experience in gaining access to appropriate assistive technology.

Consequences Summary

Consequences have been discussed in relationship to the core phenomenon of obtaining assistive technology needed for independence, the intervening conditions and the strategies discussed in preceding chapters. The main consequence of not having assistive technology is lack of participation in society. There are several barriers which have been discussed which prevent people from obtaining assistive technology and as a result create a handicap situation. Some people will go to great lengths to obtain it while others are unable or unwilling to fight for it. Within the limitations of this study, there are few consequences of not being highly involved the Independent Living Movement except for not being as visible and as assertive.

CHAPTER 9: RECOMMENDATIONS AND CONCLUSIONS

The objectives of this qualitative study were fourfold. First, the study sought to describe the assistive technology service delivery experience of urban dwelling adults with disabilities in Manitoba. Second, it sought to identify barriers and enablers in the present delivery of assistive technology in Manitoba that inhibit or promote independent living. Third, it undertook to describe the extent to which the delivery of assistive technology facilitates achievement of the Independent Living principles. Fourth, the study sought to describe the social and political context within which the delivery of assistive technology to Manitoban adults with disabilities occurred, including organizational and historical perspectives.

Major Findings

The major findings of this study will be summarized using categories based on the original objectives of the study. In general, informant narratives confirm Hahn's (1984) assertion that persons with a disability constitute a minority group and that this experience is reflected in their access to assistive technology. The narratives also confirm relationships in the Whiteneck & Fougeyrollas (1996) model of barriers creating handicap situations.

Objective 1: To describe the assistive technology service delivery experience of urban dwelling adults with disabilities in Manitoba.

Objective 2: To describe barriers and enablers in the present delivery of assistive technology in Manitoba that inhibit or promote independent living.

Based on the data collected, a general description of the consumer experience in the service delivery of assistive technology in Manitoba can be constructed. The respondents described their struggle to get adequate equipment to make their lives more independent. They did not perceive assistive technologies as luxuries, but rather as basic necessities of life that others in society take for granted.

Acquiring assistive technology is not a straight-forward process because there are a number of variables that determine whether or not an individual with a disability will obtain assistive technology. These variables include eligibility for programs or insurance benefits; funding of programs; the type and nature of the disability (situation in which it was acquired); and the individual's knowledge, "connectedness" and level of assertiveness. Respondent narratives identified no coordinated approach to accessing assistive technology. Within the government-sponsored programs there are a variety of sources, each working independently. The majority of programs are dominated by professionals which forced the consumer to deal with multiple layers of bureaucracy. Health reform and government cutbacks have impacted on the effectiveness of these programs in delivering assistive technology. At the same time, individuals with a disability are living in a society where there are rapid advances in assistive-technology; a proliferation of assistive technology vendors; increased recognition of the social participation and rights of persons with disabilities; and increased environmental access.

More choice and control can be achieved if an individual has access to resources to purchase equipment. More money is available to those who are “lucky” enough to have had an accident and qualify for insurance. Some purchase their own equipment, but most persons with disabilities do not have jobs that will support these extra expenses.

Once in the appropriate delivery system, individuals with disabilities encounter a variety of barriers which further restrict access to equipment. These include the lack of information about products and services, the complicated eligibility requirements in many programs, the inflated costs of these specialized products, complicated and convoluted bureaucracies, restricted opportunities for choice among alternative products, attitudes of professionals and vendors, and the built environment's lack of accessibility. The findings of this study confirm the complicated bureaucracy which controls access to social supports described by Dunn (1994) and the problems of eligibility and costs of social supports described by Torjman (1993).

Depending upon the length of time they have had their disability, their assertiveness, and their connections, individuals with disabilities will use different strategies to acquire equipment. These include "playing the game" in their interactions with the system and professionals, seeking out peer support to acquire product information and developing resource networks to get things faster. Other strategies included speaking up in articulating their needs to professionals, inventing assistive technology to overcome cost constraints, compensate for lack of information among providers, or develop a unique product fitting the individual's specific needs.

For many, the barriers to access were too formidable and they reported that they

gave up. Many people do not get the assistive technology that is available because of limitations in the government-sponsored programs and their lack of personal income. This means individuals in Manitoba do not reap the full benefits of assistive technology despite the exponential growth rate in assistive technology products. If people do not get adequate assistive technology, they also are unable to participate fully in the community and are effectively “handicapped”. In economic terms this may mean fewer people participate in the work force and have less buying power.

Objective 3: To describe the extent to which the delivery of assistive technology facilitates achievement of Independent Living principles.

Based on the data collected, it appears that the delivery of assistive technology in Manitoba deviates in several ways from Independent Living (IL) principles. All of the recognized IL principles - consumer control, peer support, the ability to take responsibility and take risks, and make choices - seem to be violated to some degree in the delivery of assistive technology.

Table 6, p. 195, compares and summarizes IL principles with themes identified by respondents in their descriptions of the government-sponsored assistive technology delivery system. The government-sponsored program is depicted from the data as the most restrictive. In the categories of insurance, wherein more choices are available, and in having one's own money, fewer IL principles are violated.

Despite the rise of the Independent Living movement, assistive technology is still by and large delivered in a professionally dominated manner . There is still a great deal of

social control over this technology with multiple bureaucracies deciding who will get what and when. This control is consistent with the findings of Brooks (1991).

Particularly striking was the fact that some of the individuals classified as IL-involved needed this equipment badly enough and were sufficiently intimidated to “play the game” in conforming to the professional and bureaucratic expectations of the system.

Table 6

**Relationship Between Independent Living Principles and the
Government Sponsored Assistive Technology Program**

Independent Living Principles	Government Sponsored Assistive Technology Program
Ability to Take Risks	<ul style="list-style-type: none">- choices are made for the consumer- consumers must go along with professional decisions- few options
Control	<ul style="list-style-type: none">- little access to information- must go along with professional advice- vendor often not talking to consumer-perceived power differential between consumer and professional-get what is given to you- consumer does not hold the purse strings
Peer Support	<ul style="list-style-type: none">- not sanctioned/recognized by the government sponsored program- not recognized by professionals- mainly underground
Partnership	<ul style="list-style-type: none">- power differential- professional seen as only expert

Objective 4: To describe the social and political context within which the delivery of assistive technology occurred to Manitoba adults, including organizational and historical perspectives.

Four methods of assistive technology acquisition were described including government-sponsored programs, private or public insurance, the use of the consumer's personal financial resources or a combination of the three. These methods were compared and it appeared that, as an individual moved away from the government-sponsored programs, he/she gained more control, more choice and more responsibility. All of these benefits of moving outside the present system are consistent with the principles of the Independent Living movement. However, respondents were not advocating a totally privatized system, instead they preferred a new improved government-sponsored system which incorporated Independent Living principles.

The delivery of assistive technology is set against several backdrops. As has been described, the rise of the Independent Living movement, an increase in the number and types of assistive technology products, a proliferation of assistive technology vendors, and an advancement of laws related to accessibility and assistive technology in the United States seem to affect Canada indirectly. At the same time, the Federal government is questioning its role in supporting services for persons with disabilities. There are cutbacks in health care delivery, to disability advocacy and to support for organizations and programs relevant to the disability community. A move toward the privatization of health care in Canada also seems evident. At a recent government-initiated hearing related to the Federal Social Policy Review held in August, 1996 in Winnipeg, Manitoba, representatives of the federal government asked disability groups to discuss what the role of the federal government should be with respect to disability services and programs. The overwhelming response from consumers and representatives of consumer organizations was that the federal government must continue to support programs and organizations and should set standards of service delivery. The Council of Canadians with Disabilities (1996) prepared

a position paper for the meeting outlining measures for the federal government to consider to reduce the extra costs entailed in having a disability. These proposals included tax credits, federal-provincial coordination and legislative reform. The position paper emphasized that many persons having disability-related expenses are not reimbursed. According to Statistics Canada, in 1990, 33% of those adults with disabilities aged 15-64 made such expenditures (*A Portrait of Persons with Disabilities, 1995, p.63*). According to the position paper, people with disabilities are too poor to garner any benefit from the present Disability Tax Credit. Dunn (1994) pointed out, that on the one hand there is a movement towards accepting more independent living policies, and on the other hand there have been profound reductions in public expenditures in the 1990s which have created serious problems for many consumers with disabilities.

The data from this study show a lack of recognition by government-sponsored programs and by professionals of peer supports in the delivery of assistive technology. There also seems to be a lack of recognition of the importance of assistive technology by government-supported programs. Assistive technology does not seem to be recognized as a means to achieve greater independence and lesser dependence by persons with disabilities nor as a cost saving measure. Instead, this technology is still defined by the system as "medical devices" rather than recognizing it as independent living technology. The data show that the programs in Manitoba continue to support only basic self-care needs, thereby encouraging the medical model and professional control rather than community integration. This confirms Seelman's (1993) findings.

The evidence from these data also suggests that, despite rhetoric about the community-based programs and more consumer-centred practices, assistive technology is still delivered within a system which applies a medical model. In many cases, access to technology still requires the consumer to obtain a doctor's signature or hospital visits for occupational therapy and rehabilitation engineering assessments. Respondents indicated that they felt that doctors did not know enough about assistive technology to make them the gatekeepers. As well, evidence from this study shows that, even when a person has used a device for a long time and wants to replace it with the same device when it has

worn out, the individual must get a health-care professional's assessment. This contributes to the feelings suggested by the respondents that they are not believed and that they are not experts about their own circumstances. The professionals discussed by the respondents were most often occupational therapists who did not deliver services using the "client-centred" approach that the profession espouses.

Findings Beyond the Original Objectives

Confirmation of Persons with a Disability As a Minority Group

The evidence from this study confirms Harlan Hahn's (1984) assertion that persons with disabilities constitute a minority group (disadvantaged group). Despite the fact that assistive technology can make persons with disabilities virtually independent in the environment, many respondents in this study struggle to get what they need or do not have their needs met. Despite the fact that most people interviewed were employed and were well educated, many failed to gain access to the technology that they required. Assistive technology is seen by the system and by some consumers as a luxury rather than as a necessity. Some of those interviewed apologized for wanting more equipment.

Another factor supporting Hahn's characterization of disability as a minority group is the power differential discussed between professionals, bureaucracies and the consumer with the disability. The system and professionals were perceived to exercise an inappropriate level of control over access to these important devices.

Despite progress in environmental access, persons with disabilities are still faced with inaccessible environments. The acquisition of assistive technology and the greater environmental access resulting from it do not appear to be major goals in government-sponsored programs. If government is reflective of society and this attitude prevails within society, the value society places on persons with disabilities is questionable. Many aspects of the delivery of assistive technology impose barriers and create a handicapping situation

for the person with the disability, thus supporting the Whiteneck & Fougeyrollas (1996) model.

Facilitators to Overcome the Barriers to Getting Assistive Technology

Respondents in this study offered many solutions or facilitators to overcoming the barriers that currently exist to getting assistive technology. These are grouped into five categories.

Changes to the Government-Sponsored Assistive Technology Program

One of the main points emerging from the respondents' solutions was that they wanted the government-sponsored program to continue. However, they wanted changes to it including implementation of policies supporting options for consumers to have the money in hand that is allotted to them so that they could purchase their own goods and services. Maintenance, repair services and funds to purchase new equipment were also important issues to be considered in a re-structured program. The respondents recognized the increase in the number of vendors and in the range of assistive technology products and wanted to have the ability to make choices and to take risks. They recognized the need for some sort of gatekeeper mechanism; some suggested that a panel of professionals and peers be established to monitor the system. This option of having the money in hand is similar to the present self-managed care program in Manitoba wherein the individual hires and fires his/her own attendants but receives money from the government to pay for this service. This program recognizes that not all individuals are capable of handling a self-managed care program. This approach should also be considered in a revised assistive technology delivery system. Another solution identified by respondents was to provide the individual with tax credits for the purchase of assistive technology.

Government Funding of A Product Display Centre

Better access to information including the formation of a product display centre, staffed by professionals and peer counsellors, was another important solution suggested by

the respondents. Many respondents felt that a centre was necessary to see what the options were, to test products and to keep themselves abreast of changes in the area. Some respondents suggested that products available from the government-sponsored programs also be made available at the product display centre.

Changes in Professional and Vendor Attitudes

The respondents did not want to divorce themselves totally from professionals. In fact, many described some very favourable experiences with professionals. What they do want is to work in collaboration with professionals as partners; they want to be recognized as experts on their own bodies and circumstances. They recognize that there are some important times when a professional opinion is necessary but suggest, however, that the gatekeepers be separated from the professionals who perform the assessments. They also suggested the need for a change in the attitudes of both professionals and vendors.

Recognition of Peer Supports for the Acquisition of Assistive Technology

A fourth aspect that arose in this study was the importance of peer supports to a person wishing to acquire assistive technology. Of particular interest was the use of formal peer supports. Advice from peer counsellors employed by consumer organizations was often perceived by respondents to be more important for some aspects of decision-making than professional opinions. There should be more recognition of this in professional training and government-sponsored programs.

Move From A Medical/Traditional Rehabilitation Model to An Independent Living Model of Assistive Technology Service Delivery

These four main suggestions would move the present delivery of assistive technology away from a medical/traditional rehabilitation model to more of an Independent Living model as described by DeJong (1979). The proposed model would also hopefully decrease much of the bureaucracy, red tape and unnecessary professional assessments all of which cost the system money. A product display centre would not only

provide information for persons with disabilities, it would also provide much needed information for professionals who also have difficulty keeping up in the ever-changing world of assistive technology. Many suggestions were made to discard terminology such as “medically necessary “ equipment and adopt the concept of technology “needed for independent living”.

Summary of Major Findings

Consumers’ experience of getting assistive technology in Winnipeg is generally one of frustration and struggle to get what is required. Many do not get what is needed. Several barriers described in the study interfere with the acquisition of assistive technology. These include: the lack of information, inflated costs, eligibility requirements, complicated bureaucracies, the lack of choice, inadequate relationships with professionals and vendors, and the inaccessibility of the built environment. Other barriers not described by the respondents but implied from the study encompass factors in the social and political environment, including the societal attitudes toward persons with disabilities; the lack of laws guaranteeing environmental access, and lack of recognition of the importance of assistive technology in government policy.

Some respondents have developed strategies to overcome the barriers described in the study including “playing the game”, seeking peer support, developing resource networks, inventing assistive technology and speaking up for what they need. However, applying these strategies requires a certain amount of assertiveness, initiative and skill which many people do not possess. Some people do without needed technology rather than developing these strategies. Several facilitators were suggested by the respondents to overcome barriers to getting assistive technology. These included changes to the government-sponsored assistive technology program, government funding of a product display centre, changes in professional and vendor attitudes, and recognition of peer supports for acquisition of assistive technology. These facilitators would culminate in a move from a medical model toward an independent living model of service delivery.

Modified Conceptual Model

The development of a modified conceptual model is actually the development of a grounded theory for the study (Strauss and Corbin, 1990). The findings of this study indicate that the initial conceptual model (described in Chapter 3) does not adequately reflect what is experienced by persons with disabilities in getting assistive technology. The initial model (Figure 11 p.204) did not adequately reflect the barriers, facilitators or strategies used by persons with disabilities to get their assistive technology. Therefore the model has been modified (Figures 12& 13 p. 205, 206) in an attempt to reflect the study's findings and to remediate the shortcomings of the initial model. This refined model represents the experience of acquiring assistive technology by the adult with a disability in Manitoba. The model has been divided into two diagrams: the first reflects what is currently happening, as perceived by the respondents. The second demonstrates how assistive technology services could be delivered if the suggested facilitators are put in place.

Acquiring Assistive Technology: The Current Situation (Figure 12 p.205)

The top box represents the adult with a disability in Manitoba who wishes to acquire assistive technology (bottom circle). If individuals take a direct route, they must pass through several barriers. To circumvent these barriers individuals may develop strategies. Those who do not develop these strategies may do without assistive technology.

Acquiring Assistive Technology: The Proposed Situation (Figure 13 p.206)

This model is similar to the current situation except that primary barriers are removed and facilitators are added. The facilitators are based on suggestions from the respondents in this study as to what would facilitate acquiring assistive technology. It is assumed that if the facilitators are in play rather than the barriers, consumers will have to rely less on individual adaptation strategies. For instance, playing the game and speaking up would not have to be used as much. Peer supports would be part of the suggested

facilitators. It is difficult to say if some of the same strategies such as invention and resource network development would still be used but it would seem that these approaches would be used to a certain extent.

Components of the Model

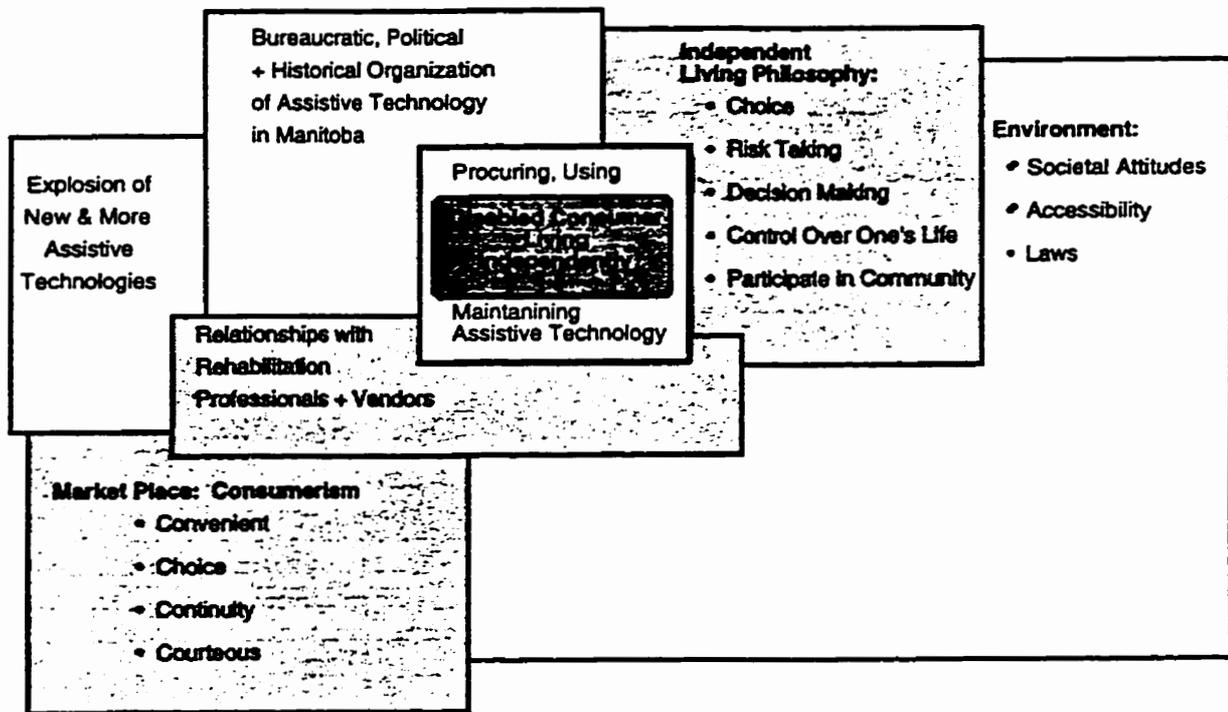
Barriers include those previously mentioned from the study data and include the lack of information, cost, eligibility requirements, complicated bureaucracies, inadequate relationships with professionals and vendors and the lack of accessibility of the built environment. Barriers also include societal attitudes toward people with disabilities, the lack of laws regulating accessibility and the lack of recognition for the importance of assistive technology.

Strategies are the positive ones that were described in the study and include the development of resource networks, the seeking of peer support, and the invention of assistive technology.

Facilitators include movement toward an Independent Living model of assistive technology service delivery. This model includes giving more power and control to consumers, decreasing the amount of bureaucratization, changing professional attitudes and providing consumers with the means to purchase assistive technology, either through the provision of funds to them directly or through reimbursement via tax credits. The development of a product display centre staffed by professionals and disability peers was also proposed as a facilitator.

Figure 11

Model of Relationship Between the Assistive Technology System The Consumer with Disabilities and Wider Social Constructs



Model illustrates how the disabled consumer's ability to live independently is embedded in broad social constructs. Barriers + Enabling factors will affect the individuals ability to live independently.

**Modified Conceptual Model
The Experience of Getting Assistive Technology
in Manitoba (Present Situation)**

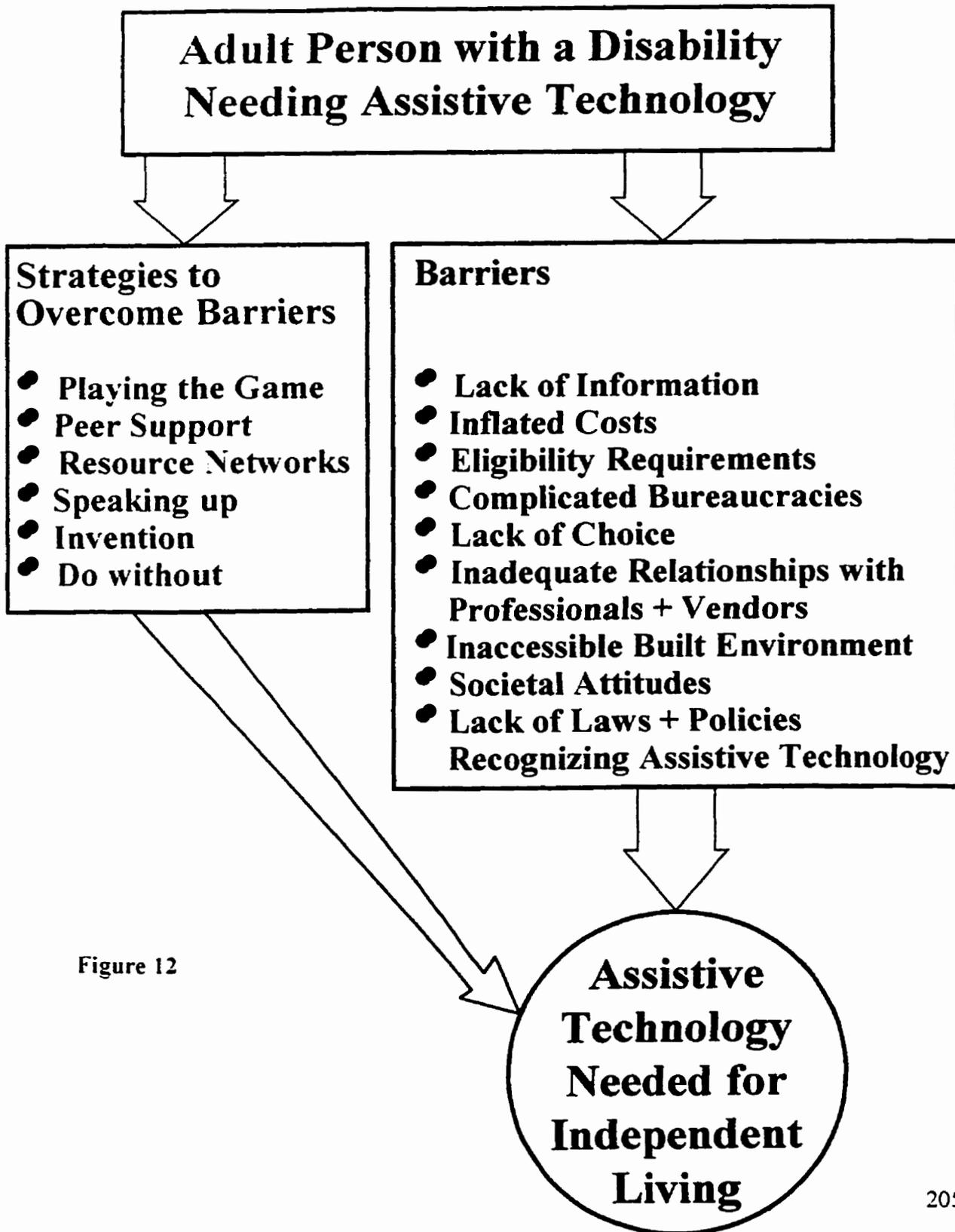


Figure 12

**Modified Conceptual Model
The Experience of Getting Assistive Technology
with Proposed Facilitators**

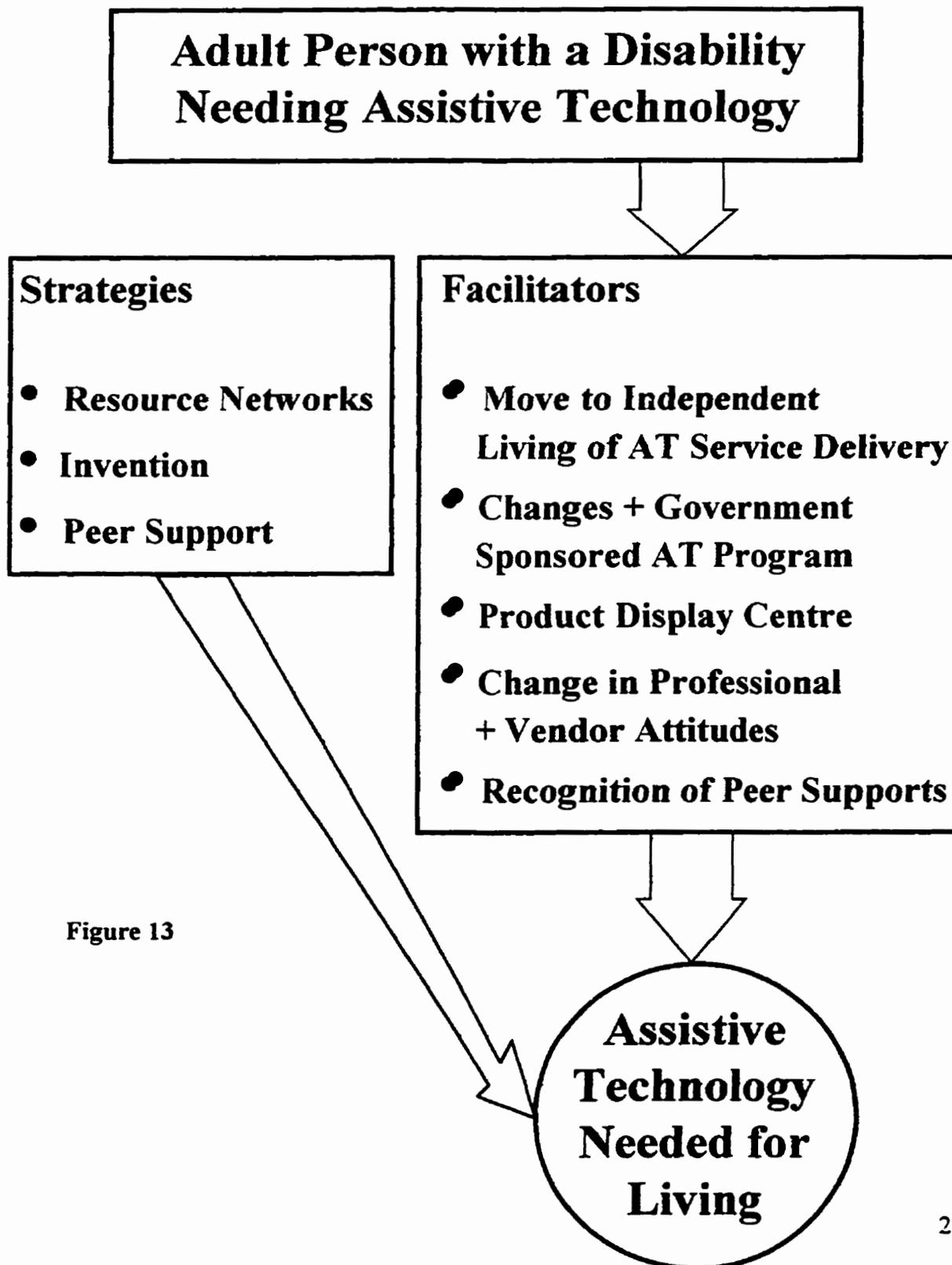


Figure 13

Study Limitations and Methodological Issues

In retrospect, a number of comments can be made about the limitations and methodological issues raised by this study, particularly with respect to A) sampling, B) attempts to describe the social-political context of the delivery of assistive technology in Manitoba, C) the difficulty in describing programs in a state of flux within the health-care system, D) the comparison of IL and non-IL involved individuals, E) the investigator's insider perspective and the F) limitations of the proposed critical ethnography approach.

Sampling

There were several limitations related to sampling. Many of the respondents came from the Fokus housing complexes. Although attempts were made to sample people from CPA and from Lions Riverside Estates, only two more people volunteered. As well, only two people volunteered as the result of the snowball sampling. A more rigorous advertising campaign would be suggested for future studies including advertising in disability organization newsletters. The sample may have been biased because many respondents came from Fokus units and therefore may have shared common experiences. One major limitation of this study was its focus on urban dwelling middle-aged adults with mobility and agility impairments. Seniors, aboriginal people and rural dwelling adults were not included. Persons with communication impairments, sensory impairments such as hearing and vision impairments, and cognitive impairments were not included. Adoption of these exclusion criteria made it impossible to explore these groups in terms of their experience in acquiring assistive technologies within special delivery systems. Most people had had their disability for several years; there was only one individual who was recently injured. Thus, the perspective of those with newly acquired disabilities could not be portrayed. Most of these respondents were fairly active in their communities and a high percentage were employed. Employment of many included professional jobs: executive directors of organizations, a professor, and a psychologist. Thus this sample had

a high proportion of individuals who were employed and had a high level of education. This demographic profile of the sample does not parallel the overall profile of the population with disabilities in Canada which depicts persons with disabilities at a much higher rate of unemployment and having lower educational qualifications than the general public.

A major limitation of any qualitative study is the sample size and the limitations in generalizing the study's findings to larger populations. However, a qualitative study's lack of statistical significance is compensated for by its richness in documenting details of the individual experience.

Attempts to Describe the Social-political Perspective of Assistive Technology in Manitoba including Organizational and Historical Perspectives

Although I thought that I could make an extensive review of this objective, I managed only a cursory job. I found that it was very difficult to obtain documents from the various agencies. As well, to have provided a more complete organizational perspective several interviews would have been required with key informants representing these agencies. These key informant interviews would have supplemented the information available in the brief pamphlets and documents which were provided to me. A thorough analysis of this objective would become a study in itself. Due to the limitations and time constraints imposed by the Masters thesis, this area was not studied extensively.

The Difficulty of Studying a Program when the Health-Care System is in a State of Flux

This study occurred over a two-year period during which time the health-care system and all services and agencies for persons with disabilities were in a state of flux. Services appeared to change from month to month. This changing context made collection of accurate and up-to-date information on service delivery very difficult. As well, what

the respondents said two years ago may have changed if they were asked the same questions today. However, having said this, I believe that many of the central issues remain the same.

Comparison of IL versus Non-IL individuals

At the beginning of the study I thought that I could compare the two groups as separate entities. As I progressed through the interviews, I began to realize that these were not two mutually exclusive groups. For instance, some people classified as Non-IL had been involved with advocacy 15 or 20 years previously. How much of this earlier experience did they retain? Are they totally out of touch with the current IL philosophy? I did not explore the issues to any extent since it seemed to go beyond the boundaries of this study. As well, for those who had not been involved with an advocacy group but lived in the community, how much of the IL philosophy was spilling over? In other words, the two groups could be said to be "contaminated" by a range of experience with the consumer movement. To acknowledge this possibility, I treated the entire sample as a whole and made only occasional references to differences. As well, the sample size itself makes it difficult to make any statistically significant comparisons between the two groups.

The Insider Perspective

As was mentioned previously, many of these respondents were known to me. I also sought out some respondents that I had never met. Being an insider, I was able to set up interviews and establish rapport quickly with several individuals including those IL-involved. Inability to gain this trust can be a problem in some studies. However, it is possible that the respondents discussed issues in a manner differently from what they may have done with a different interviewer.

Critical Ethnography

This study only developed partial data for a critical ethnography. To develop a more complete study, interviews with the key informants among assistive technology providers and assistive technology service providers should be carried out. For instance, interviews with personnel from Rehabilitation Engineering, occupational therapy and Home Care would generate data which could be compared and contrasted with the study respondents' narratives. As well, observation of interactions between the persons with disabilities and the service providers would be very useful. The final aspect of the critical ethnography - the bringing back of those interviewed for a feedback session and focus group- will occur after the thesis defence.

Implications of Findings

The findings of the study, the modified conceptual model and the study limitations and methodological issues identify many questions and issues which may provide direction for future research as well as for informing policy and practice.

Directions For Future Research

Although this study has addressed many questions, it has also identified many others that could be explored in future studies. These relate to the following areas: the modified conceptual model and other possible areas of exploration.

Questions from the Modified Conceptual Model

The modified conceptual model or theory of what it is like to acquire equipment in the delivery of assistive technology in Manitoba was previously presented (Fig 12 & 13) and is supported by the narratives of those interviewed for this study. It is not known to what extent this model applies to seniors, aboriginal people, the parents of children with disabilities, people in rural areas and people with sensory, cognitive or communication

impairments. Are additional or different strategies required by those living in rural or aboriginal communities or for those who cannot speak for themselves? What about new immigrants to Canada? One major question that must be answered is: which strategies are used to overcome specific barriers and which are connected?

Additional questions raised by the model relate to the individual sub-components. Are some of them more important than others? Does the importance vary over time, with changes in health care, with IL involved versus non-involved individuals? Will the proposed facilitators actually change the process?

Ultimately, the model that emerged needs to be tested to see if it has broader applicability. Although it appears to fit well with the experience of the 17 persons in Winnipeg interviewed for this study, the usefulness of the model can only be determined through further explorations regarding the experience of acquiring assistive technology, including qualitative, quantitative and mixed method studies.

Other Areas to Explore

There are several questions that have arisen from this study that point to further research needs.

One wonders how much more independent these individuals would be if they had all of their assistive technology requirements met with the most up-to-date equipment. One way of studying this would be to compare a group that receives equipment from insurance or legal settlements with a group who acquired a similar disability in a non-traumatic manner and who had less access to assistive technology resources.

There is a need to explore the experience of professionals such as occupational therapists and rehabilitation engineers and vendors in the assistive technology system. What is their perception of their relationship with persons with disabilities?

The relationship between the built environment and changing assistive technology needs to be studied. For instance, some of the building code guidelines do not accommodate changes in technology such as the increasing use of scooters.

If a proposal for a product display centre and the “gatekeeper” panel of peers and professional is ever accepted by government, researchers need to consider the effectiveness of these control mechanisms. As well, if consumers are given the opportunity to self-manage their assistive technology acquisitions and services, how many will want to or will be capable of doing this?

Further study is required into the experience of those individuals who are not as assertive and who are less connected with resource networks than most respondents in the study. For instance, seniors with cerebral vascular accidents (CVAs) are a group that is not well connected to a disability group. What percentage of persons with disabilities is like this and is doing without equipment? How long does it take to build a resource network? Why do they not build up a resource network? What are the abilities necessary to do this? Can they be learned? What is the best way to teach them?

The invention of assistive technology is an interesting area for future exploration. How many people do this? How do they become inventors? The process of seeking out information, the conceptualization of a device and the communication necessary for someone to produce the device takes a great deal of skill. Can this process be learned? Does the skill to invent arise out of necessity, interest or are these people born inventors? How safe are some of the inventions?

Further study is needed in the area of peer support. How many people use formal and informal peer support? How important is this support to the acquisition of assistive technology? How does peer support compare to professional advice, from occupational therapists or rehabilitation engineers?

Very little research has been carried out on the primary focus of this study - the consumer perspective of assistive technology. Most studies have either used survey methodology to examine the numbers of devices used and the reasons for their abandonment or were case studies on the effectiveness of one type of device. More research is necessary to document the psycho-social and social-political perspectives of assistive technology.

Policy Implications

A New Government Sponsored Assistive Technology Program in Manitoba

One of the main policy implications of the data collected in this study is that the provincial government should change its method of delivery of assistive technology. Respondents called for less bureaucracy and less professional control. Respondents have suggested a self-managed assistive technology option where they are provided with the money to purchase their own assistive technology from vendors and could make their own decisions about professional assessments and repair services. This would offer them more choice and control. They do not want to do away with the present program including the wheelchair repair service, but are suggesting improvements. They also suggest that a panel of persons with disabilities and professionals act as gate-keepers to prevent abuse of the system. They recognize the importance of professional assessments, but feel that these are not warranted for every piece of assistive technology. They assert that the government must also recognize the importance of peer support with respect to assistive technology and support the role of disability organizations as a vital part of the system.

Along with this revised program, they propose a government funded Product Display Centre which is staffed by persons with disabilities and professionals. This would allow both persons with disabilities and professionals a chance to see and try out assistive technology. It would also be an information source. At the time of this writing, ProductAbility is providing information only, and is receiving very little funding from the provincial government, but this could be expanded to fill this need.

Recognition by Government Agencies and Insurance Companies of Independent Living Needs versus Medical/Vocational Needs

Another strong policy-related message that was identified in these data, is the need for government agencies and insurance companies to look beyond medical need or vocational need for assistive technology. To use the term "independent living needs" would be much broader and would also take government and insurance programs out of the medical model. The use of current terminology of "medical need", "medical equipment" or even "health care equipment" creates confusion and denial of perfectly reasonable equipment requests such as wheelchairs (Donovan et al, 1987).

Recognition of Assistive Technology As An Economically Sound Investment

In order for these changes to occur, all levels of government must understand the importance of assistive technology. They must begin to realize that this equipment will end up costing them less by allowing more independence in all aspects of life including self-care, productivity and leisure. If people are able to work, they are able to contribute to the economy. To facilitate this understanding, disability advocacy groups will have to lobby government for change. It is hoped that the information developed from this study will aid in these lobbying efforts.

Practice Implications for Professionals, Vendors and Disability-related Organizations

Professionals

There is a need to examine the relationships between professionals and consumers and to develop partnerships, rather than power differentials. The area of assistive technology can potentially feed into a power differential because of the amount of information available and the danger of professionals seeing themselves as an "elite" or as

gatekeepers regulating access to the technology. It is necessary not to forget that the person with a disability is a consumer of the professional's service. This person is an expert on his/her needs and knows most about his/her body. Redefining the working relationship between professional and consumers efficiently brings together two bodies of knowledge in a framework of equality and co-participation.

Occupational therapists should incorporate assistive technology training sessions for consumers into their programs. Topics could include: how to work with a vendor, how to create a resource network, how to find information on assistive technology and perhaps how to invent one's own assistive technology when necessary. These sessions should be developed in conjunction with disability-related organizations such as Independent Living Resource Centres or local branches of the Canadian Paraplegic Association for instance.

There is a need for professionals, such as occupational therapists, to recognize the importance of peer support in the area of assistive technology acquisition and to provide consumers with the information they need to explore the possibilities and make decisions when consuming their service.

Professionals must keep up-to-date with current developments in assistive technology as the demands of consumers for quality increase. In 1996, assistive technology credentialling was established by RESNA, the North American assistive technology organization which includes professionals, vendors and consumers. This will be one method of ensuring quality of services for consumers.

Vendors

Vendors should realize the perception that some consumers have of them: people "pushing the sale", who are not consumer oriented. The latter image and relationship may change when the consumer has more control over purchases. However, as was discussed in this study, sometimes even when the consumer was paying, the vendor spoke only with the therapist. Vendors also need to consider their locations. Persons with disabilities want to see their products, but many vendors are located in outlying industrial areas rather than in local malls. Although a mall location is more expensive, it would enable more customers

to visit the stores. Perhaps multiple vendors could share mall space and keep their industrial sites for manufacturing.

Disability-Related Organizations

Disability-related organizations such as the Independent Living Resource Centres and the Canadian Paraplegic Association should set up assistive technology training sessions for consumers. Suggested topics could include: how to work with a vendor; how to work with professionals; how to set up a resource network; how to select assistive technology; how to manage resources related to assistive technology; how to find out information; how to invent assistive technology and how to work with peers. Some of these workshops could be held in conjunction with occupational therapists.

These organizations also need to pay attention to the needs of the newly injured, seniors and non-spinal cord injured persons who seem to get lost in the assistive technology maze. Further lobbying efforts are required by these groups to get government agencies and insurance companies to recognize assistive technology, not only as important to the independence of persons with disabilities, but also as an important cost-saving measure to them, enabling individuals to participate more fully in society including participation in the workforce.

Implications Summary

Policy implications identified in the respondents' narratives included the suggestion for a new government-sponsored assistive technology program, recognition by government agencies and insurance companies of independent living needs versus medical/vocational needs. Policy makers must also recognize that assistive technology is an economically sound investment by government agencies serving persons with disabilities. Finally respondents highlighted practice implications for professionals, vendors and disability-related organizations.

Conclusion

This study has presented the experiences of 17 adults with disabilities in the delivery of assistive technology in Manitoba over the time period of 1994-1995. The respondents discussed the importance of assistive technology to their lives, not only functionally but also psycho-socially. They discussed the confusing and frustrating maze that they must traverse to get the equipment that they need. Their frustrations with various barriers they have encountered and the strategies they have developed to overcome these barriers have been discussed. Respondents have provided insights and concrete proposals to improve the methods of delivery. This study has framed these data within a critical ethnographic approach and has, to some extent, critiqued the social-political world that forms the backdrop to assistive technology service delivery.

It is clear from the data that our present service delivery system is often more handicapping than enabling. Assistive technology is not a luxury. It means freedom and the right to work, go to school, and play in society for someone with a disability. It is hoped that this study will assist in not only alerting professionals, vendors and policy makers about problems in the delivery of assistive technology, but also in providing some suggestions for change. It is also hoped that this study will assist in the lobbying efforts of disability consumer groups to promote change so that persons with disabilities can more readily acquire the assistive technology needed for independent living.

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APPENDICES

Appendix A-1: Letter of Request and Letter of Permission for Use of Reprints from Whiteneck & Fougeyrollas, 1996 Model

Appendix A: Description of Ten Ten Sinclair and Fokus Housing

Appendix B: Letters of Entry

Appendix C: Information About the Study (Paraphrase)

Appendix D: Screening Interview

Appendix E: Consent to Participate in Study

Appendix F: Record of Interview

Appendix G: Interview Procedures

Background Information Questionnaire

Core Interview Guide

Separate Questions to ILInvolved Consumers

Separate Questions to non-IL Involved Consumers

Appendix H: Invitation to participate in Forum

Appendix I: Data Analysis: Summary Form Sample

Appendix J: Time Line

Appendix K: Letters Requesting Information

**Letter of Permission for Use of Reprints From Whiteneck & Fougeyrollas 1996
Model**

Laurie Ringaert, Director
Canadian Institute for Barrier Free Design
Faculty of Architecture
University of Manitoba
Winnipeg, MB R3I 2N2
December 4, 1996

Patrick Fougeyrollas, President
Canadian Society for the ICIDH
1399 Thieodeau
Box 225
Lac St. Charles, Quebec, GOA 2HO

Dear Patrick,

I am writing to request your permission to utilize your model - "Determinants of Handicap" and to make use of its concepts throughout my Masters thesis. Specifically, I would like to photocopy and include the drawings attached. My thesis is entitled **The Delivery of Assistive Technology Viewed from the Consumer Perspective: Independent Living Conditions.**

This replication is not-for-profit and is for one time use only. In writing articles for professional journals, I would like your permission to quote from your writings on this model, as necessary.

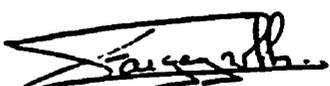
I have enclosed duplicate copies of this letter. If you agree to my request, would you please return one of them with your signature in the necessary space with a note of the date. One copy is for your reference. I would also appreciate knowing the exact way in which you would like to be referenced - the standard "Reprinted with kind permission from author, Patrick Fougeyrollas" or with some mention of your Society in the acknowledgement?

Thanking you in advance for your co-operation, I remain,

Sincerely,


Laurie Ringaert per Sarah Yates

I agree to this reproduction and usage for scholarly purposes only.

 7th January 1997

Patrick Fougeyrollas

SOCIÉTÉ CANADIENNE DE LA
COMITÉ QUÉBÉCOIS SUR LA

CIDIH

CLASSIFICATION
INTERNATIONALE
DES DÉFICIENCES,
INCAPACITÉS ET
HANDICAPS .

Dear Laurie.

You could say "Reprinted with kind permission
from author, Patrick Fougeyrollas, ~~Chair~~ President,
Canadian Society for the ICIDH.

With my best wishes for 1997

Patrick Fougeyrollas.

Case postale 225, Lac-Saint-Charles
(Québec) Canada G0A 2H0
Téléphone: (418) 529-9141/#202
Télécopieur: (418) 529-7318

PATRICK FOUGEYROLLAS
Président

APPENDIX A: DESCRIPTION OF TEN TEN SINCLAIR AND FOKUS HOUSING

(Based on information supplied by these organizations)

Ten Ten Sinclair

The primary function of Ten Ten Sinclair is to serve as transitional housing where persons with a variety of physical disabilities can gain practical experience in all areas of daily living. The goal is to develop the skills and the resources needed to lead an independent lifestyle in the community.

To be eligible for tenancy, the individual must have a physical disability which has a significant impact upon the ability to perform activities of daily living.

Fokus Housing

Fokus Housing is a system of housing and staff support services. Accessible suites are located in designated apartment blocks. On-site attendant care, meal preparation, and house keeping services are available in each block. It is designed for those who have demonstrated the capacity to manage their own affairs. To be eligible the person must have a physical disability and require attendant services and they must be over the age of 18 and eligible for Home Care Services. Currently there are four Fokus units in Winnipeg.

**APPENDIX B:
LETTERS OF ENTRY**

- **Appendix B-1: REQUEST TO ENTER 1010 SINCLAIR**
- **Appendix B-2: INTRODUCTORY LETTER TO CONSUMERS NON-IL INVOLVED**
- **Appendix B-3 INTRODUCTORY LETTER TO CONSUMERS IL**
- **Appendix B-4 REQUEST TO ENTER RIVERSIDE LIONS ESTATES**
- **Appendix B-5 REQUEST FOR ASSISTANCE FROM THE CANADIAN PARAPLEGIC ASSOCIATION**
- **Appendix B-6 FURTHER INFORMATION FOR CPA**
- **Appendix B-7 LETTER TO CPA MEMBER**
- **Appendix B-8 POSTER ADVERTISING FOR VOLUNTEERS**

Appendix B-1

REQUEST TO ENTER 1010 SINCLAIR

Date:

Mr. Milton Sussman,
Managing Director
1010 Sinclair and Fokus Housing
1010 Sinclair Avenue
Winnipeg, Manitoba
R2V 2Y5

Dear Mr. Sussman,

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my studies, I will be doing a research study. I am writing to you to describe the study and to invite your facility's participation.

The study is called " The Assistive Technology System Viewed through the Consumers' Eyes". I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists individuals with disabilities in living independently such as: wheelchairs, environmental control systems, bathroom equipment etc. I would like to talk to a number of people from 1010 Sinclair and Fokus Housing. Each interview would take approximately one-and-one-half hours at a time and place of the individual's choosing.

I would like your permission to approach residents in your facility. I propose to do this by way of an introductory letter and a follow-up phone call. To do this, I require from you, a list of names addresses, and phone numbers of potential study candidates.

Attached please find a summary of the project proposal. If I haven't heard from you, I will contact you within the next two weeks to discuss the request with you. Please call me if you have any questions at 256-9005.

I am looking forward to speaking with you.

Sincerely,

Laurie Ringaert

Appendix B-2

INTRODUCTORY LETTER TO CONSUMERS NON-IL INVOLVED

Date:

Dear Consumer:

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my program, I will be doing a research study. I am writing to you to describe the study and invite your participation.

The study is called
**" The Assistive Technology System Viewed Through the Consumer's Eyes:
Independent Living Considerations"**.

I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists you in living independently such as wheelchairs, environmental control systems, dressing aids, bath aids, etc. I plan to talk to a number of people like yourself who live independently in the community.

Information about the study has been provided to you along with this letter. If you decide to participate, you will answer a screening questionnaire. If you are eligible for the study, I will talk to you for approximately one-and-one-half hours at a time and place of your choosing.

Please contact me if you are interested in participating. I will answer any questions you might have. My phone number is **256-9005**.

I am looking forward to speaking with you.

Sincerely,

Laurie Ringaert

APPENDIX B-3

INTRODUCTORY LETTER TO CONSUMERS II

Date:

Dear

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my program, I will be doing a research study. I am writing to you to describe the study and invite your participation.

The study is called " The Assistive Technology System Viewed Through the Consumer's Eyes: Independent Living Considerations". I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists you in living independently such as wheelchairs, environmental control systems, dressing aids, bath aids, etc. I plan to talk to a number of people like yourself who are involved in consumer organizations.

If you decide to participate, I will provide you with further information. Then I would like to talk to you for approximately one-and-one-half hours at a time and place of your choosing.

I will contact you shortly to explain more about the study, to answer any questions you might have and to find out if you are willing to participate. If you wish to contact me, my phone number is 256-9005.

I am looking forward to speaking with you.

Sincerely,

Laurie Ringaert

Appendix B-4

Graduate Student
Community Health Sciences
University of Manitoba
770 Bannatyne Ave
Winnipeg, Manitoba
January 17, 1995

Nina Woloshyn
Director: Riverside Lions Estates
188 Worthington Ave
Winnipeg, Manitoba

Dear Ms Woloshyn:

I am sending this letter as a follow-up to our telephone conversation last week.

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my program, I will be doing a research study. I am writing to you to describe the study and hopefully recruit participants for the study.

The study is called " The Assistive Technology System Viewed Through the Consumer's Eyes: Independent Living Considerations". I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists people to live independently such as wheelchairs, environmental control systems, dressing aids, bath aids, etc. I plan to talk to a number of people with similar disabilities regarding their experiences.

If individuals decide to participate, I will provide them with further information. Then I interview them for approximately one-and-one-half hours at a time and place of their choosing.

I have requested that they contact me before February 15 at 256-9005 if they are willing to participate.

I have enclosed a poster as you had suggested to aid in the recruitment. Please contact me if there are any questions.
I appreciate your assistance with this study.

Sincerely,

Laurie Ringaert

Appendix B-5

Laurie Ringaert
Graduate Student
Community Health Sciences
University of Manitoba
32 Mohawk Bay
Winnipeg, Manitoba
R2J 2C7
January 17, 1995

Harriet Hart
Acting Executive Director
Canadian Paraplegic Association
325 Sherbrook Ave
Winnipeg, Manitoba

Dear Harriet

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my program, I am doing a research study. I am writing to you to describe the study and request information on your program.

The study is called " The Assistive Technology System Viewed Through the Consumer's Eyes: Independent Living Considerations". I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists individuals to live independently such as wheelchairs, environmental control systems, dressing aids, bath aids, etc. The system I define includes a) sources of equipment: government funded programs, store front vendors b) sources of funding and c) personnel: professionals, vendors, etc.

I understand that your program either provides equipment (assistive technology) directly or provides funding for equipment. I would like to develop a profile of these services in Manitoba as part of the study. I am requesting documentation from you on:

1. the objectives of your program
2. who is eligible
3. what is provided

4. who funds your program
5. what is the procedure for the consumer to obtain equipment or funding from your program including any assessments from professionals
6. anything else that you feel would help describe your program
7. If you have any statistics that you would be willing to provide, this would also be appreciated

I hope that you will be able to provide me with this information. If you have any questions or concerns please contact me at 256-9005.

Sincerely,

Laurie Ringaert BSc., BMR-OT

Appendix B-6

Laurie Ringaert
Graduate Student
Community Health Sciences
University of Manitoba
32 Mohawk Bay
Winnipeg, Manitoba
R2J 2C7
January 17, 1995

Harriet Hart
Acting Executive Director
Canadian Paraplegic Association
Manitoba Division

Dear Harriet,

Thankyou for your assistance with finding participants and providing information for my study. As we discussed on the phone today I have provided a letter for you directed to consumers of CPA services.

You indicated that you would discuss my request at your meeting tomorrow. My requests were to:

1) find individuals who would be willing to participate in the study (by the way, they can also be individuals who work at CPA also as I have interviewed individuals from other disability organizations)

2) receive written information if possible on CPA services offered regarding assistive technology (assistive devices)

Individuals at the meeting might be interested in some background on me. I am an occupational therapist who teaches at the University and also has a private practise with a rehab engineer as consultants in assistive technology. (mainly computer access) I have also been highly involved in the

Independent Living Resource Centre, am on the University of Manitoba Centre for Disability Studies Organizing Committee, and the City of Winnipeg Accessibility Committee. I am also a member of CPA. I have a disability myself and occasionally have to use a wheelchair or scooter to get around.

Please contact me once you have decided on a plan of action.

Sincerely,

Laurie Ringaert

Appendix B-7

Laurie Ringaert
Graduate Student
Community Health Sciences
University of Manitoba
770 Bannatyne Ave
Winnipeg, Manitoba
January 17, 1995

Dear CPA member:

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my program, I will be doing a research study. I am writing to you to describe the study and invite your participation.

The study is called " The Assistive Technology System Viewed Through the Consumer's Eyes: Independent Living Considerations". I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists you in living independently such as wheelchairs, environmental control systems, dressing aids, bath aids, etc. I plan to talk to a number of people like yourself who with similar disabilities.

If you decide to participate, I will provide you with further information. Then I would like to talk to you for approximately one-and-one-half hours at a time and place of your choosing.

Please contact me before February 15 at 256-9005 if you are willing to participate.

I am looking forward to speaking with you.

Sincerely,

Laurie Ringaert

Appendix B-8: Poster Advertising for Volunteers

Research Study

Are you:

* someone who uses a wheelchair?

*someone who uses other
equipment such as bath tub aids,
lifts, environmental controls?

*between the ages of 18 to 60?

*willing to be interviewed?

Please call Laurie Ringaert at
256-9005 for more information
Call before February 15, 1995

**APPENDIX C: INFORMATION ABOUT THE STUDY
(PARAPHRASE)**

Project Title: The Assistive Technology System Viewed Through the Consumers' Eyes: Independent Living Considerations.

Investigators: Laurie Ringaert will be doing the research. She is a graduate student in the Department of Community Health Sciences, Faculty of Medicine, University of Manitoba, 750 Bannatyne Ave., Winnipeg, Manitoba, R3E 0W3. Ph. (204) 256-9005.

Dr. Joseph Kaufert, Department of Community Health Sciences is supervising the research. Ph. (204) 789-3798

Purpose of Study: The purpose of this study is to learn how the consumer with a disability views the assistive technology system and if the System assists in the process of living independently. I will be talking to persons with mobility and agility impairments and will include persons actively involved in the Independent Living Movement and those who are not.

The Interview: The study is based on an interview which usually takes approximately one to one-and-one-half hours. I will meet with participants at an agreed upon time and place.

I will ask participants background information about themselves. This information will assist me in understanding influences which affect access to assistive technology. Questions will include: what type of disability , diagnosis, age, Length of time having disability, occupation, level of education, source of income for assistive technology, address.

After this I will ask participants some questions about their experience with the assistive technology system. I will ask you about the types of assistive technology that you use now, types that you feel that you need, your experience with accessing the equipment, your experiences with persons in the System such as professionals, politicians, and vendors, your experience with issues such as training, maintenance, and repair. With your permission, I will tape record the interview. I want to tape record this interview

The Delivery of Assistive Technology from the Consumer Perspective

for two reasons. First, the interview results will be more accurate and will better represent your responses if your actual words are tape recorded instead of having me just write down a summary. Second, I cannot write as fast as people talk and the interview will go more smoothly and take less of your time if it is done this way.

Forum: After I have analyzed the data from all of the interviews, I will invite you to attend a forum composed of consumers that I have interviewed. This will be your opportunity to discuss the results and to react to them. You are under no obligation to attend this group even if you have agreed to be interviewed beforehand.

Confidentiality: Records of the interview with you will be coded only with a number and not your name so that any records of your interview could only be identified by my supervisor or me. No other person will be given any of the interview data or the records. The consent forms will be the only record with your name on it. Any reports written about this project will neither mention your name or provide any description of you that would identify you. I will treat the tape-recording of the interview in the same confidential way. However, due to the small population of Winnipeg, it is possible that some of your experiences may be recognizable. I will attempt to mask any statements that you make.

Participation: Participation in this project is completely up to you. You are under no obligation to join the study. You can decide not to join the study or to drop out at any time, even while we are talking. If you decide not to talk to me, this will not affect your receipt of assistive technology service as I am not working for any agency. Participants will be given consent forms at the beginning of the interview.

Risk and Discomfort: In all research projects carried out by the University, the person doing the project must point out any risks or discomforts for the study. I do not think this study will cause any problems for you other than 1) taking up your time to answer questions, and 2) although we don't think this will happen, asking questions that may bring up personal problems. You may refuse to answer any questions that you do not wish to answer. Just let me know if you would like to skip any questions.

Benefits: All University projects must also point out if there are any benefits for the study. I do not expect the study to have any direct benefits for you. You will not receive any payment for

taking part in this study. When completed, this research should help all those involved in the assistive technology system (including consumers, professionals, policy makers, vendors) understand barriers and enablers perceived by the consumers which limit or enhance independent living. It is hoped

that this will improve service delivery.

For More Information: If after the interview you have further questions about the study, please feel free to contact me, Laurie Ringaert. My telephone number is 256-9005. I will also be pleased to provide you with a summary of the findings if you are interested.

APPENDIX D: SCREENING INTERVIEW

Code: _____

SCREENING INTERVIEW

When I contact you, I will ask you the following questions to determine if you are eligible to participate in the study: "The Assistive Technology System Through the Consumer's Eyes".

1. Do you have a visual or hearing impairment Yes _____ No _____

2. Are you under the age of 18 or over the age of 65? Yes _____ No _____

3. Do you have any of the following assistive equipment:

wheelchair, environmental control system, special lift, bathseat, dressing aids, feeding or eating aids, toilet seat, car modification Yes _____ No _____

Anything not listed here? Please describe: _____

4. Do you have a mobility impairment? Yes _____ No _____

**5. Do you have an agility impairment? (difficulty with bending, dressing, getting in or out of bed, cutting toenails, grasping objects reaching or cutting food)
Yes _____ No _____**

**6. Are you a member of a disability organization?
If yes, which one?**

7. If you are a member, what is your level of involvement? (committee member, executive position, volunteer, employee)

***** If you have answered "yes" to questions 1-2 or "no" to questions 3,4,5 above, then you will likely be ineligible for this study. I thankyou for your time.**

I will be contacting you soon.

Laurie Ringaert

APPENDIX: E

CONSENT TO PARTICIPATE IN STUDY

This consent form indicates that I, _____
(please print name in full) agree to take part in the study, "The Assistive Technology System Viewed through the Consumer's Eyes". I have been given the researcher's name and university address, and an oral and written explanation of the study.

I have been given the chance to ask questions and understand that I can ask more questions at any time. I realize that I can choose to take part, or not to take part in this study and that I can stop the interview at any time. My decision to take part or not to take part in this study will not affect the way I am treated in the assistive technology system. I have been told this study may not benefit me in any way. However, my participation will help add to the knowledge about consumer's concerns about the assistive technology system.

I understand that all information will be kept as confidential as possible, however, due to the small population of Manitoba, it is possible that some personalities may be recognized.

My signature on this page indicates that I understand and agree to take part in the study.

Date

Signature of Participant

Signature of Witness

Would you like a copy of the summary of results? _____

If yes, send to:

I have fully explained to _____

(print name in full) the nature and purpose of this research project as described on the information sheet which has been given to the participant. I have asked the participant if she has any questions about the study and have answered these questions to the best of my ability.

Date

Investigator: Laurie Ringaert

APPENDIX F: RECORD OF INTERVIEW

Record of Interview

Code: _____

1. Date of Interview: Month/Day/Year _____

2. Start _____ End _____ Length _____ Hours _____ Minutes _____

3. Physical Setting: _____

4. General Directions to Researcher:

1. Information about the study: leave with participant
2. Consent Form: leave copy with participant
3. Background information
4. Oral interview
5. Field notes

6. Any other person you would recommend?

APPENDIX G: Interview Procedures

- | | |
|---------------------|---|
| Appendix G-1 | Background Information Questionnaire |
| Appendix G-2 | Core Interview Guide |
| Appendix G-3 | Separate Questions to Consumers Highly Involved in the Independent Living Movement |
| Appendix G-4 | Separate Questions to Consumers Not Highly Involved in the Independent Living Movement |

APPENDIX G-1:

Code: _____

BACKGROUND INFORMATION QUESTIONNAIRE:

1. Describe your disability:

Agility (difficulty with tasks requiring your hands)

Mobility _____

2. How long have you had your disability?

- 1) since birth
- 2) since childhood
- 3) since adolescence
- 4) since adulthood

3) In which age range do you place yourself?

- 18 - 25
- 26 - 35
- 36 - 45
- 46 - 55
- 56 - 65

4) With whom do you reside?

5) If you do reside with someone, does this individual assist you with any of your every day tasks?

6) Are you presently

- 1) Working Full Time
- 2) Working Part Time
- 3) Unemployed
- 4) Retired
- 5) Full-time Homemaker
- 6) Student

12) How long have you used assistive technology devices?

13) What type of devices do you currently use"?

CORE INTERVIEW GUIDE

Note: Questions listed here are merely a guide for the researcher. Questions will not necessarily be asked verbatim as written in this list, some questions may be omitted or expanded upon depending on the direction the interview takes. Note: In this interview the words assistive technology, equipment and devices are used interchangeably, depending upon the comfort level of the participant. Wording will be explained to the participants.

Grand Question:

"Describe your experience with the assistive technology system in Manitoba."

Specific Questions:

- 1) Describe your most frustrating experience with the current System**
- 2) Describe your most encouraging experience with the current System.**
- 3) Over the years have you seen changes in the System? Describe these changes. Describe positive and negative changes.**
- 4) What are the strongest points about the current System of Delivery .**
- 5) What opportunities do you have to make suggestions to improve the System?**
- 6) What are your concerns about the present System of delivery?**
- 7) How would you make the system work better for you? For everyone?**

Device Background

1) What type of equipment do you need but do not currently have?

2) Why do you not have this equipment?

3) How do you pay for your equipment?

1) own income

2) Government health care

3) private insurance

4) Workers Compensation

5) Autopac

6) VRDP

7) Other

4) Where do you get your assistive technology devices from?

1) Home Care equipment pool

2) Commercial vendor

3) Other

EXPERIENCE WITH ACQUIRING DEVICES

1) How do you get technology services when you need them?

2) Describe your experience with making decisions and making choices regarding

your equipment?

3) Describe how you find out about technology that is out there.

4) How do you learn to use technology devices after you receive them?

5) What do you do if you have a problem with one of your devices: for instance repairs, how it works, modifications, etc.

6) Describe your experience with risk taking and your equipment. For instance did you ever make a decision which went against a professional's opinion?

7) Do you think that the system should allow the consumer to take risks?

EXPERIENCE WITH PERSONNEL

1) Describe the input you received from assistive device professionals such as occupational therapists, physio therapists, rehab engineers, social workers, voc rehab specialists.

2) Describe the input you received from assistive device vendors?

3) Describe any situations or equipment for which you feel there is no need for rehab professional intervention?

4) When and why do you feel that a rehab professional is needed?

5) What was the involvement like of any caregivers (family or others, could be formal or informal) regarding your equipment?

6) Is there anything else that you wish to add?

**SEPARATE QUESTIONS TO CONSUMERS HIGHLY INVOLVED
IN INDEPENDENT LIVING MOVEMENT**

1) Would you describe the current assistive technology system as meeting the needs of the consumer?

2) Does the current system include principles of Independent Living such as making choices, risk taking, etc.

3) What are some of the initiatives that the consumer community has taken to make changes in the System?

4) What changes in the System would the consumer community like to see to improve it.

**SEPARATE QUESTIONS TO CONSUMERS
NOT INVOLVED IN INDEPENDENT LIVING MOVEMENT**

- 1) What do you think should be your role in decision making regarding assistive devices?**

- 2) What level of involvement should professionals have when it comes to your assistive devices?**

- 3) If a professional said you could not have a device, what would you do?**

APPENDIX H: INVITATION TO PARTICIPATE IN A FORUM

Dear

You will recall that you participated in the study "The Assistive Technology System Viewed from the Consumer Perspective: Independent Living Considerations". The data from your interview and from all of the other interviews have now been analyzed and put together into a report.

I would like to invite you to a forum composed of persons who participated in the interviews. This will give you an opportunity to see the results as well as to respond to them. It will also give you the information should you or your group wish to use it in any further lobbying efforts regarding assistive technology in the province.

You are under no obligation to attend this session. If you do not attend you will still receive a summary of the final report if you desire it. I will arrange a wheelchair accessible meeting place that is convenient. Again, your identity will be kept confidential when information from this session is published in my report.

If you are interested in attending this session, please contact me at your earliest convenience at 254-6732. If I don't hear from you within one week, I will contact you.

Sincerely,

Laurie Ringaert

Appendix I: Data Analysis Form

(Adapted from Miles, M. B. & Huberman, A. M., 1995)

Contact Summary Form

Contact #

Contact Date:

Today's Date:

- 1. What were the main issues or themes that struck you in this contact?**
- 2. Summary of info from each of the target questions for this contact.**
- 3. Anything else that struck me as salient, interesting, illuminating**
- 4. New questions to pursue:**
- 5. Agencies dealing with assistive technology mentioned in this interview:**

APPENDIX J: TIME LINE

TIME LINE

June 1994	Ethics Committee approval
Oct 1994	Access to sites approval Letters to participants
Nov 94-Feb 95	Interviews with Independent Living Involved and Non-Involved, preliminary Analysis - Development of profile of assistive technology system in Manitoba
Mar 95-Sept 96	Analysis of Data/ Writing of Thesis
Oct/96- July/97	Editorial revisions to thesis
July/97	Thesis Defence
Fall/97	Final Forum

Appendix K: Letters Requesting Information

- Appendix K-1: Letter to Home Care Equipment Pool**
- Appendix K-2: Letter to Special Devices**

Appendix K-1

Laurie Ringaert
Graduate Student
Community Health Sciences
University of Manitoba
32 Mohawk Bay
Winnipeg, Manitoba
R2J 2C7
January 17, 1995

Margaret Gaune
Home Care Equipment Pool
1500 Regent Ave

Dear Margaret:

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my program, I am doing a research study. I am writing to you to describe the study and request information on your program.

The study is called " The Assistive Technology System Viewed Through the Consumer's Eyes: Independent Living Considerations". I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists individuals to live independently such as wheelchairs, environmental control systems, dressing aids, bath aids, etc. The system I define includes a) sources of equipment: government funded programs, store front vendors b) sources of funding and c) personnel: professionals, vendors, etc.

I understand that your program either provides equipment (assistive technology) directly or provides funding for equipment. I would like to develop a profile of these services in Manitoba as part of the study. I am requesting documentation from you on:

1. the objectives of your program
2. who is eligible
3. what is provided
4. who funds your program
5. what is the procedure for the consumer to obtain equipment or funding from your program including any assessments from professionals
6. anything else that you feel would help describe your program

The Delivery of Assistive Technology from the Consumer Perspective

7. If you have any statistics that you would be willing to provide, this would also be appreciated

I hope that you will be able to provide me with this information. If you have any questions or concerns please contact me at 256-9005.

Sincerely,

Laurie Ringaert BSc., BMR-OT

The Delivery of Assistive Technology from the Consumer Perspective

Appendix K-2

Graduate Student
Community Health Sciences
University of Manitoba
32 Mohawk Bay
Winnipeg, Manitoba
R2J 2C7
January 17, 1995

Paul Tuston
Special Devices
Health Sciences Centre
800 Sherbrook
Winnipeg, Manitoba

Dear Paul:

I am a graduate student at the University of Manitoba in the Department of Community Health Sciences. As part of my program, I am doing a research study. I am writing to you to describe the study and request information on your program.

The study is called " The Assistive Technology System Viewed Through the Consumer's Eyes: Independent Living Considerations". I am interested in talking to persons with mobility and agility impairments who have had experiences with the assistive technology system. By assistive technology I mean specialized equipment that assists individuals to live independently such as wheelchairs, environmental control systems, dressing aids, bath aids, etc. The system I define includes a) sources of equipment: government funded programs, store front vendors b) sources of funding and c) personnel: professionals, vendors, etc.

I understand that your program either provides equipment (assistive technology) directly or provides funding for equipment. I would like to develop a profile of these services in Manitoba as part of the study. I am requesting documentation from you on:

1. the objectives of your program
2. who is eligible
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The Delivery of Assistive Technology from the Consumer Perspective

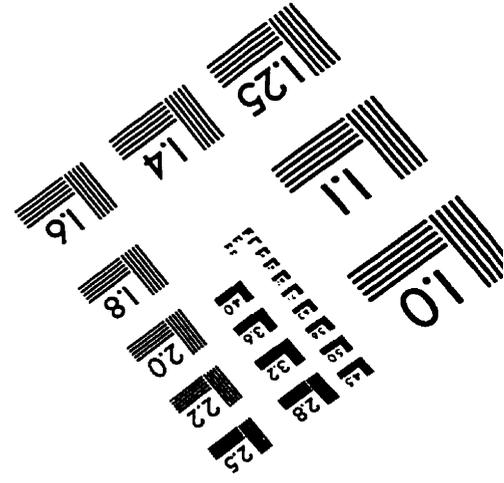
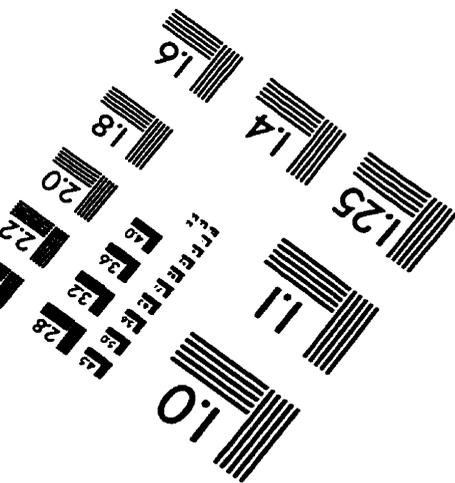
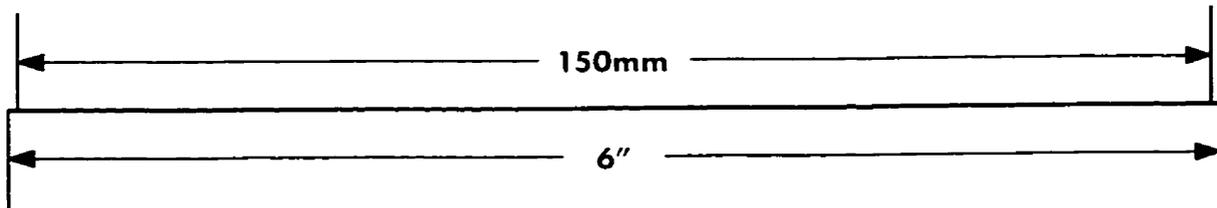
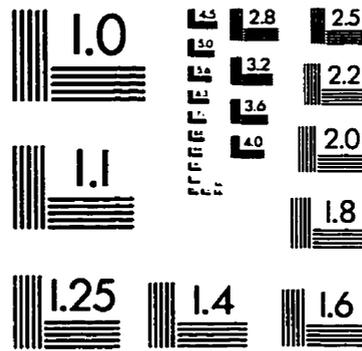
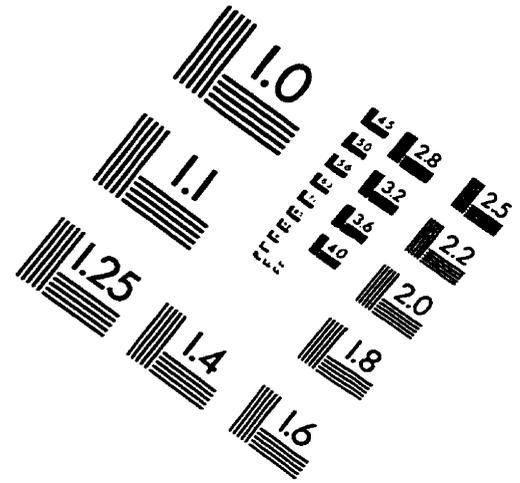
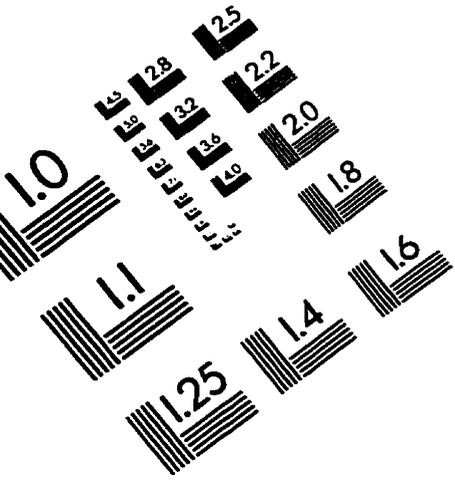
5. what is the procedure for the consumer to obtain equipment or funding from your program including any assessments from professionals
6. anything else that you feel would help describe your program
7. If you have any statistics that you would be willing to provide, this would also be appreciated

I hope that you will be able to provide me with this information. If you have any questions or concerns please contact me at 256-9005.

Sincerely,

Laurie Ringaert BSc., BMR-OT

IMAGE EVALUATION TEST TARGET (QA-3)



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