We acknowledge that there is more than one way to ‘read’ information. As a symbol of diversity and inclusion, this report features a tactile medium. A tactile image is one that you can understand by touch. This tactile, of the research logo consists of a universal female symbol (a circle joined to a T). Inside the circle is a computer-representing one kind of adaptive technology.
This document is the Full Report. The Full Report is available for download on the ILRC website: [http://www.ilrc.nf.ca](http://www.ilrc.nf.ca).

A Summary Report is available on CD (p. 24) in Rich Text Format (rtf), Microsoft Word (.doc), PDF, Braille (Duxbury) and Plain Language.

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   I. Diana L. Gustafson
   II. Independent Living Resource Centre
   III. Title

For more information contact:

Michelle Murdoch
C/O ILRC, 4 Escasoni Place
St. John’s, NL A1A 3R6
Tel: (709) 722-4031
Fax: (709) 722-0147
TTY: (709) 722-7998
Toll Free: (866) 722-4931
Email: mmurdoch@nl.rogers.com
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>1</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>2</td>
</tr>
<tr>
<td>Overview of the Report</td>
<td>4</td>
</tr>
<tr>
<td>Section 1: Introduction</td>
<td>5</td>
</tr>
<tr>
<td> Statement of Problem</td>
<td>5</td>
</tr>
<tr>
<td> Background</td>
<td>6</td>
</tr>
<tr>
<td> Significance of Study</td>
<td>8</td>
</tr>
<tr>
<td> Abbreviations &amp; Terms</td>
<td>9</td>
</tr>
<tr>
<td>  Abbreviations</td>
<td>9</td>
</tr>
<tr>
<td>  Terms</td>
<td>10</td>
</tr>
<tr>
<td>Section 2: Literature Review</td>
<td>11</td>
</tr>
<tr>
<td> Disability: Concept and Lived Experience</td>
<td>11</td>
</tr>
<tr>
<td>  Independent Living</td>
<td>15</td>
</tr>
<tr>
<td> Adaptive Technology</td>
<td>18</td>
</tr>
<tr>
<td>  The Digital Divide</td>
<td>20</td>
</tr>
<tr>
<td>  Universal Computer Access</td>
<td>21</td>
</tr>
<tr>
<td> Unemployment/Employment</td>
<td>23</td>
</tr>
<tr>
<td>  Women, Employment, Poverty</td>
<td>23</td>
</tr>
<tr>
<td>  The Elusive Workplace</td>
<td>25</td>
</tr>
<tr>
<td>  Mothers with Disability</td>
<td>28</td>
</tr>
<tr>
<td>  Federal Legislation</td>
<td>28</td>
</tr>
<tr>
<td>  Provincial Legislation</td>
<td>29</td>
</tr>
<tr>
<td> Employment, Education and Workplace Entry</td>
<td>31</td>
</tr>
<tr>
<td>Section 3: Participatory Action Research</td>
<td>33</td>
</tr>
<tr>
<td> Methodology</td>
<td>33</td>
</tr>
<tr>
<td> Principles of PAR</td>
<td>34</td>
</tr>
<tr>
<td> Research Design</td>
<td>45</td>
</tr>
<tr>
<td> Participant Selection and Informed Consent</td>
<td>46</td>
</tr>
<tr>
<td> Data Collection</td>
<td>46</td>
</tr>
<tr>
<td> Data Analysis</td>
<td>49</td>
</tr>
<tr>
<td> Tactile Medium: A Symbol of Inclusion</td>
<td>50</td>
</tr>
<tr>
<td> Research Limitations</td>
<td>51</td>
</tr>
<tr>
<td>  Barriers to Anonymity</td>
<td>51</td>
</tr>
<tr>
<td>  Fear of Repercussions</td>
<td>51</td>
</tr>
<tr>
<td>  Homogeneity of Voice</td>
<td>52</td>
</tr>
<tr>
<td> Participant Profile</td>
<td>52</td>
</tr>
<tr>
<td> Participant Technology Profile</td>
<td>54</td>
</tr>
<tr>
<td>  Computer Use</td>
<td>54</td>
</tr>
<tr>
<td>  Adaptive Technology</td>
<td>55</td>
</tr>
<tr>
<td>Section 4: Findings and Recommendations</td>
<td>57</td>
</tr>
<tr>
<td>Section 5: Summary</td>
<td>65</td>
</tr>
<tr>
<td>References</td>
<td>67</td>
</tr>
<tr>
<td>Appendix A</td>
<td>72</td>
</tr>
</tbody>
</table>
**Figures**

Figure 1: Representation of Employment: Women with Disabilities. Federal, Provincial and Territorial Ministers Responsible for Social Services (2000).

Figure 2: Canadian Labour Force Activity for Women and Men With and Without Disabilities is based on Statistics Canada (2001).

Figure 3: Labour Force Activity for Men and Women With and Without Disabilities is based on Statistics Canada (2001).

Figure 4: Education Trends women and men with disabilities upon completion of high school is based on Statistics Canada (2001).

**Tables**

Table 1: Representation of Participants According to Age. Women with disabilities and adaptive technology: Application to participate. Appendix A.

Table 2: Participants' Reported Experiences using Adaptive Technology Women with Disabilities and adaptive technology: Application to participate. Appendix A.
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**Principal Investigator:** Michelle Murdoch, RN BVoc Ed, MWS (candidate)

**Co-investigator:** Diana L. Gustafson RN BA MEd PhD.
Division of Community Health, Memorial University of Newfoundland

**Co-investigator:** Mary Reid, Executive Director, Independent Living Resource Centre, 2004

**Co-investigator:** Barry Galloway, Executive Director, Independent Living Resource Centre 2005
EXECUTIVE SUMMARY

This report provides an overview of a research project that examined the experiences and perspectives of unemployed, underemployed, and employed women with disabilities, and their knowledge of and need for adaptive technology. While sustained and satisfying employment and economic self-sufficiency are critical to the health and social well-being of all Canadians, study participants reported a serious lack of access to the labour market. This is despite high school, post secondary education and knowledge of how to use a computer.

Reasons women with disabilities experience systemic obstacles to the labour market are complex. Implicated in the problem is the very use of the word disability. Disability is a fluid and evolving term that has not been adequately defined in a manner that has pleased all stakeholders. Likewise adaptive technology is often defined by academic and technology experts. Women in this research reclaimed their ‘right’ to define adaptive technology and its implications within their lives. Women described a litany of systemic obstacles that have encumbered their entry into the labour market. It became apparent that until these issues are addressed it is unlikely adaptive technology will fully impact the lives of women with disabilities.

This report represents the collaborative efforts of twelve women with disabilities from St. John’s, Newfoundland and Labrador, two Executive Directors of the Independent Living Resource Centre in St. John’s, a university academic with the Division of Community Health at Memorial University of Newfoundland, and a woman with disabilities who is both a graduate student in the Women’s Studies Program at Memorial University of Newfoundland and an active member of the Independent Living Resource Centre.

Participatory action research was the research method used to identify and report study findings. The guiding principles of participatory action research are consistent with the Independent Living Principles that guide the Independent Living Resource Centre. Both sets of principles promote and support women with disabilities in controlling their own personal experiences, making informed choices, taking risks with the choices made, and taking
responsibility for those choices. The twelve women who took part in the study are called participants. As the name suggests a fundamental aspect is that the research remained participant driven. This means participants are involved throughout the research process including the editing and dissemination of the final report.

The Independent Living Resource Centre is committed to respectful, consumer-driven research that will enhance the centre’s research and development goals. Academic involvement with representatives of the disability community formulates new relationships and supports high academic standards throughout the research process and product. The benefits of working in collaboration with the research participants include: improved research designs, enhanced implementation, increased community ownership of health initiatives and increased credibility and sustainability of outcomes for women with disabilities.

We found that despite education, work experience, and involvement in various training programs the majority of women with disabilities were unable to find sustained employment with a living wage. Although most women with disabilities have improved access to education, policies to advance use of adaptive technology in the labour market have not kept pace. Consequently, women with disabilities are demonstrably and significantly excluded from employment.

This report concludes with eighteen recommendations that must be addressed to open doors to the labour market for women with disabilities. Women with disabilities, researchers, employers and policy makers in the public, private and volunteer sectors must use their collective power to re-examine actions or inactions that promote exclusion of women with disabilities from gaining full citizenship.
This report is written in 5 sections. Section 1 provides the reader a brief introduction into the background of the problems experienced by women with disabilities in relation to employment. There are a number of abbreviations used within this report and it is here these terms are defined.

Section 2 includes a literature review. There are many ways the subject of employment, women with disabilities and Adaptive Technology could have been approached. We selected three topics for discussion; disability, Adaptive Technology and employment. This information provides the backdrop to the research project.

Section 3 speaks to the methodological approach of this research. We evaluated four principles of participatory action research and some of the realities that hold the potential to challenge these principles. This is where you will find a description of data collection, data recording and data analysis. There is a detailed sketch of the participants including general technology and Adaptive Technology profiles.

Section 4 describes research findings and recommendations. Findings were gathered primarily by input from participants and supported by information assembled throughout the literature recommendations are participant driven and supported by consensus of the entire research team.

Section 5 summarizes the report conclusions and makes recommendations for the future. Group interview and the personal interview sessions as well as subsequent informal discussion yielded a significant amount of information. Due to the density of this information and the limitations of time and space, it was not possible to address every point brought up by participants. However, from these points we gather suggestions for future research.
Statement of Problem

Women participating in this research report they cannot gain access to sustained and satisfying employment. This is despite high school and post secondary education as well as familiarity of how to use a computer.

The intent of this research was to focus on women’s knowledge of and experience with computers and adaptive technology (AT) as tools for facilitating successful integration into the workplace. Once we gathered to speak it soon became apparent that women do not consider AT their solution to unemployment and underemployment. Participants claim other barriers must be addressed before the full potential of AT can be reached.

“I’m sure there are other devices out there that could help me with my typing or boosting my confidence with regards to obtaining meaningful employment but I’m not really sure what is available or what can help.” 1

1. Quotes are by participants, all of who wished to remain anonymous and without pseudonyms.
**Background**

According to the federal government Office of Disability Issues or ODI (2002) half of all working-age Canadians with disabilities are unemployed. When data are broken down by gender some sources report that 40-75% of women with disabilities are unemployed, underemployed or living below the poverty line (DisAbled Women’s Network Canada, 2003; ODI, 2002; Masuda, 1998; and Pierson and Cohen, 1995).

*In Unison 2000*, a report issued by the Federal, Provincial and Territorial Ministers Responsible for Social Services states employment rates differ significantly between women and men without disabilities and women and men with disabilities. Men without disabilities experience an employment rate of 91% and women without disabilities an employment rate of 76%. When participation into the workforce is distinguished by disability, statistics are considerably different. About half (49%) of men with disabilities are employed compared to 38% of women with disabilities.

**Figure 1: Representation of Employment: Women with Disabilities (In Unison, 2000).**

Both women and men with disabilities face considerable obstacles gaining labour force entry. That 62% of women with disabilities want to work and are unemployed is startling. Figure 1 demonstrates employment statistics for women with disabilities across Canada (*In Unison, 2000*). It does not distinguish in terms of full time, part time, under or contingency employment.
Of the 38% of women with disabilities who were employed in 1995 only 14% worked full-time for a full year (*In Unison 2000; ODI, 2002*). This means that few women have a reliable and sustained income that provides a living wage. In addition women generally earn a lower income than men.

Information from the Department of Human Resources and Employment, Government of Newfoundland and Labrador (January 2002) states women with disabilities have:

- less access to employment overall
- less opportunity for full time employment
- an income less than men

These are some of the indicators that prompted this research to be gendered.

The Disability Rights Movement created a social model of disability that assumes that all persons with disabilities have a right to equal and full participation in society (Charlton, 1998, Enns & Neufeldt, 2003). For women with disabilities, full participation is reflected in economic self-sufficiency. To become economically self-sufficient, women with disabilities must have sustained employment in environments that accommodate individual needs (Feika, 2003). Currently, universal access to a computer via AT is regarded by some experts as the tools of choice for providing some of this workplace access (Cunningham & Coombs, 1997). It is suggested access to AT holds the potential to expand employment opportunities for women with disabilities.
Significance of the Study

This project assumed that sustained and satisfying employment and economic self-sufficiency are critical to the health and social well-being of all Canadians. Women with disabilities have significantly higher rates of unemployment and underemployment than their male counterparts and women and men without disabilities. This study builds on the premise that suggests women with disabilities must become technologically efficient to be taking advantage of compensatory tools for workplace accommodation (Cunningham and Coombs, 1997).

This research project provides a venue through which women gathered and expressed their lived experiences about employment, underemployment or unemployment. Included as well, are women who were attending post secondary schooling. It was thought women actually in school would be able to speak not only to the educational experience but also to their plans for the future.

There were four objectives identified in the research proposal:

1. Investigate how computers and adaptive technologies influence women’s experiences of employment and seeking employment [and thus maintain or mitigate differences in employment rates in this population].

2. Create sustainable collaborative relationships between ILRC, academics and potential employers to support transition into sustained employment for women with disabilities.

3. Identify mechanisms for sharing information about AT with other potential users.

4. Evaluate the value of the CAP program at the ILRC in meeting users needs for knowledge and information about AT.
# Abbreviations & Terms

## Abbreviations:

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>AT</td>
<td>Adaptive Technology</td>
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<tr>
<td>CCDS</td>
<td>Canadian Centre on Disability Studies</td>
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<td>CCSD</td>
<td>Canadian Council on Social Development</td>
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<tr>
<td>CNL-CAP</td>
<td>Canada Newfoundland and Labrador - Community Access Program</td>
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<tr>
<td>Co-Is</td>
<td>Co-Investigator</td>
</tr>
<tr>
<td>DAWN Canada</td>
<td>DisAbled Women’s Network, Canada</td>
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<td>DAWN Ontario</td>
<td>DisAbled Women’s Network, Ontario</td>
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<td>DRM</td>
<td>Disability Rights Movement</td>
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<td>HALS</td>
<td>Health and Activity Limitation Survey</td>
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<tr>
<td>HIV/AIDS</td>
<td>Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities and Handicaps</td>
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<tr>
<td>IL</td>
<td>Independent Living</td>
</tr>
<tr>
<td>ILRC</td>
<td>Independent Living Resource Centre</td>
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<tr>
<td>MUN</td>
<td>Memorial University of Newfoundland</td>
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<tr>
<td>NL</td>
<td>Newfoundland and Labrador</td>
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<tr>
<td>ODI</td>
<td>Office for Disability Issues</td>
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<td>PALS</td>
<td>Participation and Activity Limitation Survey</td>
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<td>PAR</td>
<td>Participatory Action Research</td>
</tr>
<tr>
<td>PI</td>
<td>Principal Investigator</td>
</tr>
<tr>
<td>RA</td>
<td>Research Assistant</td>
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<tr>
<td>UCA</td>
<td>Universal Computer Access</td>
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<td>WHO</td>
<td>World Health Organization</td>
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**Terms**

**Independent Living Movement**, as a social movement, speaks to the rights of an individual or group to work together to advance the rights and freedoms of all people with disabilities. Key to IL are the concepts of self help and self determination.

**Disability community**: For the purposes of this paper the term disability community refers to individuals that self-identify as members of a group identified by society as ‘disabled’. This is not to suggest a homogeneous voice but rather emphasis is placed on a person’s ability to decide for herself whether or not she wishes to be part of this community. This is also called **self determination**.

**Self identify** is a major concept within the Independent Living Movement. This refers to the individual’s right to choose how she wishes to be identified or not.

**Self help** happens when a person has the supports she needs to control her own life experiences.

**Oppression** is well defined by Charlton. He states, “Oppression occurs when individuals are *systematically* subjected to political, economic, cultural, or social degradation because they belong to a social group. Oppression of peoples results from structures of domination and subordination and, correspondingly, ideologies of superiority and inferiority” (1998, p. 8).

**Disability Oppression** is a complex and partial form of oppression directly linked to the concept of disability.

**Consumer**: Within the context of Independent Living the consumer is the person with a disability. It is meant to describe a sense of self control not found in other more ‘traditional’ labels such as patient or client.
“And it’s nice to have choice—that sort of gives us a little bit of power too”

This literature focuses on three areas of primary concern throughout this research project, they are:

1. Disability: Concept and Lived Experience
2. Adaptive Technology
3. Unemployment/Employment

Even within our small group of women each of our experiences are unique. We come from varying social economic privilege, some of us were born with disabilities and some acquired them later in life, and some have the advantage of post secondary education while others have been denied what most would consider a basic level of education. Some of us have AT in our lives, some of us do not want it, and yet others dream of possessing it!

**Disability: Concept and Lived Experience**

“The struggle shouldn’t be for integration, but for power. Once we have power, we can integrate whenever we want.”


The word ‘disability’ encompasses a wide range of meanings and very often the people who supply the definition are not those who will have to deal with its implications. There is no single, unified and accepted definition of disability. There is however, often great pressure to produce a definition of disability as representative of a universally accepted concept.

The Disability Rights Movement challenges the concept that those who are not directly impacted by the experience of living with a disability feel they hold the cognitive authority to adequately determine the paradigms of disability. Cognitive authority refers to those who
hold the power to make such determinations. Wendell (1996) writes, “’cognitive authority’ is a term I borrow from feminist philosopher Kathryn Pyne Addelson. It means the authority to have one’s description of the world taken seriously, believed, or accepted generally as the truth” (p. 117). She takes the approach that those who have the power to define disability should be, but are likely not, those who have the disabilities.

In 2002, on recommendation of the House of Commons Subcommittee on the Status of Persons with Disabilities, work began on a document to define disability. Based on committee recommendations, a report called Defining Disability (2003) was published. In it disability advocates, academics, mental health representatives, and medical professionals present their views on establishing a definition. While government and community agencies called for greater consistency of interpretation, it was generally suggested that perhaps ‘disability’ cannot be defined in absolute, all-inclusive terms.

The report states the complexity of issues involved.

Many people argue that there is no simple way of defining disability. One definition of disability that fits all circumstances may not be possible or even desirable. Disability is difficult to define because it is a multi-dimensional concept with both objective and subjective characteristics. When interpreted as an illness or impairment, disability is seen as fixed in an individual's body or mind. When interpreted as a social construct, disability is seen in terms of social, economic or cultural disadvantages resulting from discrimination or exclusion (Defining Disability, 2003, p. 39).

A model is a tool from which to gain a perspective other than the one we already know (Finkelstein, 2004). Models tell us how we arrange different things; theories tell us why we have labels such as “disabled.”

The Canadian government recognizes three conceptual models:

1. The impairment perspective
2. The functional limitation perspective
3. The ecological perspective.
The impairment perspective may be best represented within the medical model of disability in which the ‘experts’ are the medical professionals. Disability is seen as an impairment of the mind, or the body, or both, that should be fixed or at least treated.

Medical authority extends beyond the patient-physician relationship and out into general society (Wendell, 1996). Wendell claims, “… authority operates far beyond medical institutions – inside and in relation to government bureaucracies, insurance companies, courts, schools, charities, rehabilitative organizations, and institutions for long-term care” (p. 117). Thus the medical authority extends beyond the physician’s office and into our everyday lives.

The social authority of knowing permits medical experts to determine the boundaries of disability within many facets of society, particularly in areas beyond medicine such as education. The problem with the impairment perspective or medical model is that the experts are medical authorities as opposed to those who live with the impairment. People with disabilities are seen as in need of treatment or fixing.

The functional limitation perspective, an expansion of the medical model, attempts to quantify disability by degree of physical and social limitations imposed by physical or mental impairment.

In 1980 The World Health Organization (WHO) presented the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This is the first major classification system to focus specifically on disability. According to the ICIDH, disability refers to any reduction or lack of ability, caused by impairment, to perform an activity in a way considered normal for a human being (ODI, 2003). The federal government often uses this linear type of perspective to provide disability statistics. In 1986 and 1991, statistics were provided using a well-known model called the Health and Activity Limitation Survey (HALS).

In 2001 this model was replaced with a more modern ecological perspective, the Participation and Activity Limitation Survey (PALS). The federal government touts PALS as the primary
data source for all aspects of disability (ODI, 2003). In 2001 PALS became the main
disability source for data related to employment, education, income, supports such as tax and
financial measures, and access to housing, transportation, recreation, leisure, health care and
volunteer activities. While PALS continues to identify people with disabilities using the 1980
ICIDH functional limitations approach, the disability framework outlined by its successor,
the 2001 International Classification of Functioning, Disability and Health (ICF), is evident
throughout the survey (ODI, 2003, p.9)

The problem with the functional limitation perspective is that persons with disabilities are
still viewed as categories of ‘receivable benefits’. PAL is not a perspective that serves to
empower individuals who historically have been oppressed by the values in mainstream
society.

Note: the word ‘handicap’ is sometimes used to describe impairment or physical/mental
limitation. Participants in this research study rejected any use of the word ‘handicap’. They
felt the term was representative of an individual with her cap held out to passersby begging
for money. This was not the image women wanted attached to them.

The ecological perspective rather than accepting the idea that authoritative knowledge arises
from medical knowledge; this model portrays the experts of disability as those who have
lived the experience. It is often referred to as the social model of disability (Oliver, 2004;
Finkelstein, 2004; and Thomas, 2001, 2004). In North America, the social model of disability
gathered momentum following the American civil rights and second wave feminist

During this time the social perception of people with disabilities began to change. People
with disabilities challenged social barriers that inhibited full citizenship of disability. Oliver
head and argued that it was not our impairments that were the main cause of our problems as
disabled people, but it was the way society responded to us as an oppressed minority” (p. 7).
From Oliver’s point of view, the concept of disability would be very different if society in
general radically altered its perspective. For example, until the arrival of the Internet, western society viewed print text as a mainstay of communication. With the advance of technology, print options have extended to include electronic text as well. Electronic text (which enables font and background color change) combined with voice reader systems (voice output systems) or text enlargers offers the potential to a diversity of alternative texts.

Yet, some disability activists suggest that envisioning disability totally from the social model, while it improves on the medical model, does not provide enough room for discussion about bodily or mental impairment (Thomas, 2001; 2004; Wendell, 1996). Many factors promote or fail to prevent disease, sickness or injury: disease or sickness brought on by wars, lack of food, clean water, poor working conditions, and poor or inadequate medical care. Good medical care, which saves lives but is unable to prevent all physical or emotional change resulting from such an experience, also has the potential to produce more disability. Wendell writes, “[d]isability is also socially constructed by the failure to give people the amount and kind of help they need to participate fully in all major aspects of life in society, including making a significant contribution in the frame of work” (p.40). Some disability activists claim ‘disability’ is more widely reflective of western society’s failure or refusal to imagine solutions beyond how wide to build an access ramp. Women with disabilities need and want a more comprehensive range of support options.

**Independent Living**

The ideal that everyone could live without boundaries set by the social label of ‘disability’ if provided adequate disability-related supports is the foundation of the Independent Living philosophy. This philosophy, as part of the evolving Disability Rights Movement (DRM) grounds itself on the premise that most important is that individuals with disability achieve independence (Phillips, 2003). Charlton (1998) identifies two principles of achieving independence under this philosophy. They are self help and self determination.

Self help suggests individuals with disabilities are able to control their own personal experiences. It also refers to the fact that the experts are always those with the lived
experience of disability. Self determination rejects patriarchal ideals that individuals with disabilities must be cared for. Although we will make ‘mistakes’ women with disabilities can and should make choices for themselves, this is part of the taking risk process. Enns (2003) states fundamental to the evolving DRM is not only self help and self determination but also acknowledgement of Human Rights and full inclusion of people with disabilities within society. Full inclusion or citizenship is defined in the government report In Unison 2000 as, “… the inclusion of persons with disabilities in all aspects of Canadian society- the ability of a person to be actively involved with their community” (p. 7). In effort to be actively involved, society must first recognize barriers that support the exclusion of individuals with disability.

In the United States, the International DRM activist Ed Roberts was instrumental in challenging barriers to Independent Living (Charlton, 1998; Zames Fleischer and Zames, 2001; Enns and Neufeldt, 2003 Phillips, 2003; Enns 2003). In the early 1960’s Roberts legally challenged his right to attend Berkeley University (Zames Fleischer and Zames, 2001). Robert’s legal challenges were successful and gradually, with the support of injured World War II and Vietnam War veterans, the university began to accommodate students with disabilities. These changes did not necessarily happen easily and it was with constant vigilance that Independent Living became acknowledged. As a result of Robert’s outspoken and unrelenting challenges Berkeley University became one of the power houses of the Independent Living Movement.

Canada had proponents of Independent Living as well as World War II brought injured veterans back home. One such veteran was Tony Mann, Executive Director of the Canadian Paraplegic Association Western Division. He was instrumental in challenging the lack of physical accessibility in Canadian society. His efforts did not happen in isolation as he had strong support from other Canadian and United States activists. Over time Mann and others influenced issues such as building accessibility. Many people such as Mann dedicated large portions of their life to systematically chip away at the patriarchal structures in an effort to promote public and governmental awareness of disability issues (Ringaert, 2003).
In a sense disability advocates had their work verified in 1972 during a United Nations (UN) conference in Stockholm. During this conference it was declared public accessibility was deemed a factor that could improve a person’s quality of life. What this means is that the UN accredited the importance of all types of accessibility such as curb cuts, ramps, elevators, and access to Braille documents (to name a few). This acknowledgement by the UN jump started the process of inclusion of people with disabilities into mainstream society.

Momentum was increasing and the 1980’s brought with it monumental changes to Canadian society. The International Year of Disabled Persons in 1981-1982 progressed into the 1983-1992 Decade of Disabled Persons. With such concentration on disability issues the Independent Living philosophy flourished. This growth was supported in Canada by the development of the Charter of Rights and Freedoms Act (1982). Within this legal document disability rights were specifically articulated. All Canadians, with and without disabilities now had a degree of legal recourse to define their civil rights.

IL philosophy advocates using the term ‘consumer’ rather than patient or client. Within the context of IL, the word consumer, the person with the lived experience of disability suggests an individual capable of controlling her own life experiences, making informed choices, taking risks with the choices made and being responsible for those choices. This philosophy is most successful when the consumer is provided adequate disability supports.

This description of Independent Living in Canada represents a skeletal image of a much larger portrait. So many groups and individuals united to enforce change prompted by the deinstitutionalization and de-medicalization of disability. Thus, Independent Living provided the individual tools to transition into society. These tools are an essential step in the effort to achieve full citizenship. However the tools alone are never enough as the battle to maintain minority rights in a hegemonic society is a relentless struggle.
Adaptive Technology

“For people without disabilities, technology makes things convenient, whereas for people with disabilities, it makes things possible . . . [this] fact brings with it an enormous responsibility because the reverse is also true. Inaccessible technology can make things absolutely impossible for disabled people, a prospect we must avoid.”

—Judith Heumann as recorded by Mates. (ND)

The Roeher Institute supports the position taken by Judith Heumann that AT holds the potential to make more things possible for all people with disabilities. To be denied this is to obstruct full citizenship of people with disabilities into society. The Roeher Institute discusses disability in terms of ‘defending difference’. “A central premise underlying democracy is the belief that people are different; to believe in rights is to believe in defending difference” (2003). AT is a response to ‘defending difference’. AT offers people with disabilities the opportunity to use computers to do tasks their disability would normally prevent them from performing.

Academic experts describe AT as “computer software and hardware that have been modified to be accessible by people with disabilities, or equipment that has been created to be compensatory tools for people with disabilities” (Cunningham and Coombs, 1997, p.3). Women who are experts in the types of accommodation they need characterize AT much more broadly than technology experts. For example:

One woman put it this way: “Adaptive technology can be many things. It doesn’t necessarily have to be a piece of software or a piece of complicated equipment or something that costs three or four thousand dollars.”

“My definition of AT is any accessible thing that I require to get the job done or to get my educational goals met.”
“I think it’s whatever you need to give you a good quality of living. For me it’s a two-inch lift on my left shoe because if not I couldn’t walk across the room”.

“Well I think it could be anything from a feeding device to a computer device. It’s all adaptive”.

One participant challenges the all-inclusive ideal. The current notion of AT, she states, is “limited to anything that plugs in.” Others question this concept and speak to adjustable workstations, Braille markings, and arm supports as related to ‘adapted’ computer use but not capable of plugging into an electrical outlet. There was no consensus as to what AT actually means to each woman.

Participants expressed the opinion that they are ones to best determine their own needs. Not everyone agrees. Policy makers, academics and technologists seem to be credited as the experts while participants stated rarely are they consulted for their expertise in decisions that directly impact them.

Coming to a general agreement about what we were each referring to when we used the words AT was not easy and the conversation changed directions numerous times. There is a resistance from participants to be bound by descriptive classifications. Why is this? The use of semantics by agencies that provide disability-related supports appeared to be central to the resistance. One woman states “…if you ask me [about the word] “AT” it’s no newer than [the words] ‘disability related supports’. Other words used to describe instruments to access the computer are universal computer technology, or assistive technology. Womenspace (2004 & 2003) uses the term Information Communication Technologies or ICT’s. One participant pointedly remarked on the convenience of redefining the meaning of words related to disability has historically resulted in a simultaneous decrease in benefits or new criteria for program entry. Others agreed that semantics have been used by agencies controlling the funding for disability support systems to regulate accessibility to support and programs.
For example, a participant describes one support worker who assists her in two different job titles. When the worker is in school she is called a tutor and available through government support programs for 3 hours per week. When the same support worker assists the participant in the workplace she is called an administrative assistant. Under this label the worker is available for 40 hours per week. The participant believes both jobs serve the same purpose but the name of the job determines the amount of benefits receivable. Thus, there is reluctance to attempt to define any word. It seems it is not so much that there is no meaning attached to the word AT, but rather that participants considered AT as their word to claim ownership of (or not).

This report was participant focused and the women in this study despite (on average) high levels of education, computer expertise and desire to be gainfully employed were very much restricted by limitations created within the NL social system. Computer knowledge, skills and for most university and other forms of post secondary education had not seemed to improve their ability to obtain and sustain labour market entry. As a result participants accessed government or community agencies that are set up to navigate disability barriers to employment. Reliance on government programs and support systems was not an immediate reaction but rather a desperate attempt to gain independence. Survival within these systems appears to require significant skill, knowledge of operating systems and determination.

**The Digital Divide**

The digital divide is a term used to distinguish the gap between individuals who are able to effectively use new information and communication tools, such as the Internet and those who cannot (www.digitaldividenetwork.org). Women with disabilities who do not have the availability of an accessible computer or Internet widen the digital divide.

There is more at stake for a small group of minority women than finding themselves at the bottom of an abstract theoretical scale. Computers offer the potential to create a new public sphere of communication and employment (Neumann and Uhlenkueken, 2001). Within the space of this technology there need not be distinguishing factors such as disability.
**Universal Computer Access**

Universal computer access (UCA) means that anyone is able to use a computer and Internet. There are many ways to achieve computer and Internet access, four examples of software and hardware are:

- Text Enlarger Programs enable text to be enlarged to font of any size.
- JOUST2 Sip and Puff Device is a joystick controlled by breath intake or breath output therefore the name sip and puff. As an adjustable desktop device, it may be used with an onscreen keyboard to enable typing.
- JAWS Reader software reads information from a screen aloud. Available in 17 languages, it enables the user to find their way through software applications and the Internet.
- Handi Eye is a camera that acts as a mouse. It focuses on a woman's face. As she moves her face the cursor moves left, right, up or down. Holding the cursor over an object will click on it. She doesn't need to use her hands at all.

Computer technology is designed to be individualized. In other words what works for one person with a particular disability may not work as well for another with the same type of disability. There is software that will read aloud any type of text. The electronic text might originate from the Internet, a word document, or a book that has been entered into the computer. A person who finds reading traditional text impossible or difficult may have access to this type of reading system.

Within this research, participants who had the same type of disability requested text in a variety of forms. What this means is that methods to communicate are becoming increasingly diverse and not so ‘identifiable’ by specific disability. Originally some AT was designed to suit the needs of a particular disability. Over time however these lines of distinction have disappeared as individuals with all kinds of disability found the value of versatility in the hardware and software. A fear expressed within this research project is that directly linking one piece of technology to a specific disability restricts personal choice and access to funding opportunities.

Zames Fleischer and Zames (2001) discuss reports from research within the United States concerning AT and disability. They write that people with spinal cord injuries who were
computer savvy prior to acquiring a disability were more likely to attain employment post injury faster than those who were not. But overall only one third of individuals with spinal cord injury in the US are employed. Two-thirds of these employed individuals use a computer in the workplace and report no wage differential compared to their peers. The remaining one-third who did not have computer knowledge prior to their injury received substantially lower pay.

The US experience shows that despite advances in technology, the potential to create a more inclusive society is not the prevailing attitude within industry. There is “… no industry wide interest in working with the disability community…” (Zames Fleischer and Zames, 2001, p.157). Reasons given for this were the cost of AT and the cost of supplying computers to people with disabilities. While computer prices are rapidly decreasing, individuals with disabilities often do not earn an income that allows for an accessible computer. Zames Fleischer and Zames compare computer access to building accessibility. If the cost of producing accessible buildings were factored into the original design of the building, cost would be reduced and the public would get a less expensive and more accessible end product. The same is true for computers. If accessibility was considered as important as customer appeal, it would become one of the parameters in which all computer technology evolves. For example few people know of the ‘rugged computer’. This computer can be taken out in the rain, dropped, and given other forms of abuse not generally thought acceptable to other forms of laptop computers. The virtual indestructibility, while a disability-related support would likely work well in other mainstream applications.

In summary AT symbolizes more to society than convenience. It seems to represent a model of need or difference. Were prevailing attitudes to alter course, most AT offers another way to achieve the means. As the population continues to age perhaps attitudes will change.

“*There is no assistance. There is no funding. There is no expectation that if we get the technologies or the equipment or the aids that we need that we will be more productive.*”
Unemployment / Employment

“…Exclusion from the world of work is the most important factor in what happens to disabled people and the way we are treated by society”
-(Oliver, 2001, p.149).

The reality for the St. John’s women taking part in this research is that unemployment rather than employment was the primary theme of this research. We examined national and provincial employment statistics as well as employment legislation or lack thereof, followed by the relationship of education and workplace entry.

Eight of the twelve participants reported they were unable to find employment. Some reported access to short term (3-8 weeks) contractual jobs with no medical or pension benefits.

Women, Employment, Poverty

Some discussion concerning employment is applicable to all women. Women employed full time still earn, on average, substantially less than men. “Women tend to be located in non-lucrative, dead end jobs, and their salaries fall below those of men in almost all occupations and market positions” (Stier and Lewin, 2002, p. 213). Women who lack education are generally channeled into jobs with low wages, poor job security, no health benefits, and little opportunity for promotion or career advancement. Such jobs reduce a woman’s ability to be economically self-sufficient (Cranford, Vosko, and Zukewich, 2003; Stier and Lewin, 2002).

The accumulation of a number of social factors such as lower pay rates for women, less job opportunities, less opportunity for advancement and the fewer number of job hours available to women have combined to create the concept “feminization of poverty” (Stier and Lewin, 2002, p. 213). Within the disability community we rarely discuss employment in gendered form. It is less likely we would speak about feminization of poverty even though research indicates women are less likely than men to have their needs met (Fawcett, 2000).
A senior policy analyst for the Canadian Council on Social Development (CCSD) Katherine Scott (Scott and Lessard, 2002), claimed the difference between the average income of people receiving a living wage and the poverty line is called “the poverty gap”. A factor that contributes to poverty despite increases in personal incomes is income inequality. Income inequality is the difference between higher average incomes and lower average incomes. According to Guildford (2000) income inequality has significantly widened in Canada over the last twenty years. A widening of the income inequality means there is a subsequent drop in the nation’s overall health.

The World Health Organization or WHO declares all people who live in poverty experience an increase in illnesses and a shorter life expectancy than those who do not live in poverty (WHO, 2003). WHO specifically identifies people with disabilities as at risk for relative poverty, or at risk to live in an environment that is poorer than most in a society, and/or at risk to live (in varying degrees) in social exclusion. Persons with disabilities are more likely to live in an environment poorer than most because those who do work are more likely to be poorly paid, work at a “lower status”, and leave the workforce before official retirement age (Roulstone, 2004, p.195).

According to the WHO, poverty and exclusion diminishes opportunity for education, training, employment, and access to services (WHO, 2003 p.16). Income has a direct relationship to inequalities of health. “No amount of money or reform within the health care system will effectively reduce inequalities in health status until geographically-based incomes and social disparities are addressed” (Scott and Lessard, 2002, p. 2). Thus issues of poverty, disability, and employment are layered, complex and intricately interwoven.

The words women, education, and employment must be distinguished from women with disabilities, education, and employment. Social inequities exist even within the greater term of ‘women’ that should raise caution about always considering the word women as a homogeneous concept that embraces all.
Figure 2 represents the Canadian Labour Force activity reported by Statistics Canada for the year 2001. Significant in this graph is the dramatic difference in employment numbers for women and men with disabilities. This segment of the population has a significantly lower employment rate.

**Figure 2: Canadian Labour Force Activity for Women and Men With and Without Disabilities (Statistics Canada, 2001)**

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**The Elusive Workplace**

The federal government Office of Disability Issues (ODI) reveals half of all working-age Canadians with disabilities were unemployed in 1995 (Leadership Engagement Results, Strategic Plan. 2002-2007). Women with disabilities have significantly higher rates of unemployment and underemployment than their male counterparts and women and men without disabilities. Underemployment means a woman must work less time than she wishes to work or that she has a job that does not acknowledge all of their skills. In other words a woman works in a job that offers a wage lower than her earning potential.
What kind of jobs are women seeking? A good job is described as “typically full-time and full year, paid living wages and benefits … and unionized” (Luxton and Corman, 2001, p. 15). Not so good jobs are “often part-time, low paid and with few benefits … and not unionized” (p.15). A number of participants state they desire a full time job with benefits. Not everyone can work in standard type jobs.

Research from the United States indicates that rather than promoting flexibility within standard employment, employers tended to offer only contingent or part time work (Schur, 2003). Workers in these types of jobs are overwhelmingly female, young, and from impoverished backgrounds. For some women with disabilities there are positive aspects to part time employment. Part-time hours may enable transition into the workplace for those who have been off for longer periods. Part-time may work well for those with fatigue. Schur refers to part-time employment as one way to overcome issues of transportation. This would be the case only if it is the woman’s choice to work part-time work. If an individual chooses to work full-time she should have access to adequate transportation.

A fear with part-time work is that employers may not want to provide disability-related support to the worker. Schur states employers indicate they are reluctant to hire workers whose benefits are less likely to exceed their costs. Participants’ state loosing benefits such as life insurance and medical coverage may outweigh the risk involved in part time employment. Most indicate contingent employment is not a good option. It does not usually allow for arrangement of transportation in a system that requires advanced booking. This type of work makes negating disability related supports more difficult.

In regards to perceiving employment as a risk some women with disabilities in Ontario agree with the NL participants in this research (Fawcett, 2000). The women in NL and Ontario state there is a significant risk with workplace re-entry when one has disabilities. As a woman with disabilities it is more difficult to secure and maintain a stable family income. Knowing she will find it difficult to find and maintain employment and knowing the family must have some source of income to survive; women are often forced into the stable poverty of the disability support systems. While income is low on these support systems it is often more
favorable than an employment system that is three times less likely to hire a person with disability.

Women with disabilities who live in Ontario and are seeking to enter the labour market are least to find employment (Fawcett, 2000). Fawcett states, “regardless of where they live, women with disabilities are most likely to be without employment and least likely to have full-time, full-year employment” (p. 2). If this is the case in a province such as Ontario where unemployment rates are low is it predictable a similar pattern would happen in a province where unemployment rates are high?

The federal government Office of Disability Issues (ODI) claims 14% of all women with disabilities in 1995 worked for a full year. 62% of women with disabilities report they did not work at any point throughout the year. DisAbled Women’s Network Canada (DAWN Canada) declares 75% of all women with disabilities are unemployed, underemployed or living below the poverty line (2003). Other statistics suggest 40% of women with disabilities are unemployed or underemployed (Masuda, 1998). Thus statistics addressing employment issues for women with disabilities vary depending on the source.

Young women with disabilities in particular have difficulty getting work compared to young men with disabilities. Research by Doren and Benz (1998) indicates the reasons for low employment amongst young women with disabilities are complex. They report young women with disabilities are more likely to experience poorer post school employment outcomes than young men with disabilities. There are a number of reasons cited from their research that explains these outcomes. Some are:

- Young women are less likely to find paid employment while attending school, therefore young men graduate programs with more job experience.
- Unlike young men, young women are less likely to gain employment within a two-year period after leaving high school.
- Young men are much more likely to find work within one year of completing post secondary education.
- Young women exhibit lower levels of self esteem.
Mothers with Disability

One participant who is a mother of two children stated she felt her issues of employment as a single mother were somewhat different than women who did not have children. While this was not an important focus for other participants Fawcett (2000) does demonstrate a difference in need for working mothers with disabilities. Her research concerning women with disabilities in Ontario indicated:

- Women are more likely to be divorced, separated, or widowed than non-disabled women.
- Most women living alone are more likely to bear most financial responsibility for children.
- Affordability to child care would likely improve employability.
- Using disability transit systems to pick children up from childcare often involves booking two buses as most do not wait for mothers to pick up the children. Thus transportation for mothers is more expensive and time consuming.
- Not all daycare facilities are accessible.
- Women believed taking a job was a risk to their children. Although disability related supports do not equate with a high standard of living, security of some income albeit low was perceived as better than losing a job due to illness or disability related concerns.
- Women with disabilities are less likely than men with disabilities to receive help with household chores.
- Women without disabilities report a return to the workforce when children reach the age of 6. It is reported that for women with disabilities this age is 12.

Federal Legislation

Canada has Federal Employment Equity Legislation. “At the federal level, Canada’s employment equity policies and programs rank amongst the most advanced in the world.” (Bakan and Kobayashi, 2000, p. 13). The 1984 Abella Report has greatly influenced the template for the federal government employment equity policy. This report defined equity, set goals for equality, and identified the workplace as a systemic location of worker
discrimination. The importance of education and training was acknowledged within this report as a means for oppressed individuals to gain entry into the workplace.

However, despite federal government equity legislation ODI acknowledges the complexity of securing employment opportunities for minority groups such as people with disabilities. A 2004 Government of Canada Report states overall adults with disabilities are less likely to be employed than adults without disabilities (ODI, 2004). “Adults with disabilities are over three times more likely to be out of the labour force than adults without disabilities” (p. 39). Even though governments acknowledge these statistics opportunities for employment have not changed according to the women in this research.

**No Provincial Legislation**

Newfoundland and Labrador (NL) is one of two provinces, Alberta reported as the other, without employment equity legislation (Bakan and Kobayashi, 2000). *The report Investing in People: New Directions for Social Assistance Legislation* (January, 2002) provides the following information about Women who live in NL.

- On average women in NL receive an income 70.5% of their male counterpart.
- More women receive Social Assistance benefits and 23% of all people receiving these benefits do so because of illness or disability.
- Women are more likely to be employed in minimum wage jobs.
- Need for disability related supports (i.e. personal care) or equipment influences the determinations of ‘living wage’.

Social assistance may be paid to individuals who are employed but do not make a living wage or their need for disability-related supports precludes their income from being a wage that can maintain their basic needs.

Figure 3 indicates the similar employment patterns as national statistics. People with disabilities experience a drastically lower rate of employment. Numbers are taken from Statistics Canada for the year 2001.
Linked to unemployment are income inequities, issues of poverty, poor health and underemployment. “Research shows that income levels are linked to other indicators of well-being, including health status and education” (Investing in People: New Directions for Social Assistance Legislation, January, 2002, p. 15). Statistics reveal 70% of Newfoundlanders receiving Social Assistance have not achieved high school graduation. While this indicates that a significant number of people with disabilities never complete high school, participants in this research have graduated high school or its equivalent. Therefore this discussion will focus on education following high school.

NL does not have employment equity legislation or equity legislation, or pay equity legislation. Some believe legislation is necessary because low employment rates for people with disabilities indicate the desire to do the right thing is not effective (Boland, 2005). Employment equity legislation may, “address issues of workplace recruitment, retention and promotion among designated groups that experience systemic oppression in society” (Bakan and Kobayashi, 2000, p. 10).
A large number of women and men are employed in NL by the provincial government. Within this system are the Employment Equity and Strategic Initiatives. Opening Doors is an initiative targeted specifically at employment within the disability sector. Entry into the labour market through one stream of Opening Doors requires the minimum of a university degree. At present a number of these jobs are not filled partly because the jobs require training beyond what the hundreds of applicants possess. Some women expressed frustration that while they have higher education and have participated in numerous forms of assessments and work placements still find themselves unqualified for these jobs.

Some unfilled jobs are located outside of the metro area. Participants reported that it may be difficult for individuals with disabilities to relocate once they have their education because of the lack of adequate disability-related supports in rural areas. One such type of support is access to (disability) public transit. Some participants specifically identified lack of reliable and accessible transportation as a barrier to employment opportunities inside St. John’s metropolitan area but most particularly in rural areas.

**Employment, Education and Workplace Entry**

*Figure 4: Education Trends women and men with disabilities upon completion of high school*

Figure 4 depicts education trends for women and men with disabilities after graduation from high school. Overall women with disabilities outnumber men with disabilities in all sectors of post secondary education except the trades and technology sector. More than twice as
many men enter trades related post secondary education but almost twice as many more women graduate university. That fewer women attend post secondary education in trades and technology is not specific just to women with disabilities. This trend, reported by the Women in Resource Development Committee is reflective of all women in NL (Boland, 2005).

Some social researchers distinguish women as different from women with disabilities in relation to levels of education. According to these researchers, although women with disabilities may benefit from higher levels of education by an increased self-esteem, these higher levels of education for women identifying as disabled are not indicators for increased levels of employment (Nosek, Hughes, Swedlund, Taylor, and Swank 2003; Ferri and Gregg, 1998; Doren and Benz, 1998).

This perturbing observation is noted in Women, Education and Disability Research Project. This 1993 Manitoba study demonstrates women with disabilities who complete vocational or university programs display no increase in employment compared to women with disabilities who did not obtain education or training beyond high school (Scott, 1993). Advanced education offered women with disabilities increased levels of self-esteem but not increased entry into the labour market.

There is literature that suggests advanced levels of education are fundamental to improved employment opportunity (Government of Newfoundland and Labrador, 2005). A recent report by the NL government states, “Low levels of formal education are strongly related to low incomes” (2005, p.13). ODI (2004) states overall adults with disabilities have a lower level of education compared to adults without disabilities. A lower level of education is believed to be part of the reason women with disabilities face barriers to employment. However, participants in this study report completion of high school as well as substantial post secondary education (degrees, diplomas, and certificates), internships, and work placements. Many have partaken in numerous assessments such as vocational, skill development, skills upgrade, and intake assessments. According to most of the St. John’s women education, training, and workplace experience have not altered their ability to overcome the obstacles that prevent their labour market entry.
Methodology

The North American Disability Rights Movement (DRM) gained momentum following the American Civil Rights and second wave Feminist Movements. The DRM has created a social model of disability that assumes *all* persons with disabilities have a right to equal and full participation in any society (Charlton, 1998, Enns & Neufeldt, 2003). This perspective identifies full citizenship within society by endorsing and promoting the importance of basic human rights.

Supporting the DRM movement is the concept of Independent Living (IL). The IL philosophy is the opposite of the apartheid-type structure that historically separated individuals with disabilities by institutionalization. IL arose as a response to the impairment (also known as the medical/rehabilitation model) of disability. This perspective supports the concept that the individual with the lived experience of disability should identify and control her own need and life experience. In the medical model individuals with disability are viewed as in need of fixing and being cared for within the health care system.

A research method which supports the community ideal of IL is Participatory Action Research (PAR). PAR is a qualitative type of research which offers a wide range of approaches intended to build relationships with identified communities. At the same time PAR ensures some degree of shared values and social action with community members (Jason, Keys, Suarez-Balcazar, Taylor, Davis, Durlak, and Isenberg, 2004; Balcazar et al, 1998; and Reinharz, 1992).
Principles of PAR

To ensure a closer reflection of voice PAR includes participants throughout all of the research process. This is a major shift from traditional research in that at least theoretically power becomes dispersed so that participants, community partners, and researchers control outcomes.

Balcazar, Keys, Kaplan, and Suarez-Balcazar (1998) describe four principles of PAR when research includes women or men with disabilities. These principles are:

1. Individuals with disabilities themselves articulate the problem and participate directly in the process of defining, analyzing, and solving it.
2. Direct involvement of people with disabilities in the research process facilitates a more accurate and authentic analysis of their social reality.
3. The process of participatory research can increase awareness among individuals with disabilities about their own resources and strengths.
4. The ultimate goal of the research endeavor is to improve the quality of life for individuals with disabilities (p. 106-107).

1. Individuals with disabilities themselves articulate the problem and participate directly in the process of defining, analyzing, and solving it.

It is an ideal to propose that individuals with disabilities gather together to identify a research question for potential research funding. This approach enhances the possibility that identified research goals will reflect concerns of participants. This is called a grassroots approach and one that is recognized within the ILRC as optimal. We will discuss three major obstructions that challenge this ideal. They are:

a. Fiscal realities
b. Presumption that women with disabilities only experience the oppression of disability
c. Finding voice amongst women who bear a history of oppression

1(a) Fiscal realities

Costs for research planning may include transportation, childcare, disability accommodation and reimbursement for time spent in the planning sessions. Community organizations are rarely provided funding for research. While research and development is formally recognized
within the ILRC organizational chart the reality is research is a rare occurrence. Consumer need is so startling that immediate focus is on information sharing, advocacy, peer support and employment counseling. The Newfoundland and Labrador government provides funding for core services within the ILRC but this funding has not to date acknowledged the empowerment that may be gained through research activities. Given the desperate need for basic services and lack of funding to adequately meet consumer demands, many might regard funding potential research proposals as a luxury rather than a necessity.

1(b) Multiple oppressions - Oppression within oppression:
The following discussion will focus only on the oppressions of gender and disability, acknowledging there are numerous other possible combinations of oppression. It is well documented by feminist disability writers that the generic term ‘disability’ focuses primarily on that oppression and rarely any other (Garland-Thomson, 2002; Thomas 2001; Ferri and Gregg, 1998).

Historically women, men and children have been identified first by their disease. The DRM demanded individuals with disabilities should be acknowledged as persons first rather than identification by disease/illness. While ridding identification by disease is essential, over time it seems as if we have become socially identified in genderless form also referred to as ‘asexual objects’ (Garland-Thomson, 2002). Over time the word ‘person’ has been accepted language when discussing disability issues and as a result rarely we are rarely women/girls or men/boys.

Seldom referred to in terms of gender, people with disabilities begin to believe there are no gender differences. This is not true. The perception that gender may be excluded from other forms of oppression creates many possible consequences (Ferri and Gregg, 1998). Two are described here. One is that women with disabilities will not be included within the women’s movement and second that women as gendered beings will not be fully included in the disability movement. Ferri and Gregg write, “The absence of voices of women with disabilities results in an ablest woman’s movement and a sexist disability movement” (p. 429).
These findings were very much reflected in our group interview sessions. Several years ago some women with disabilities worked with representatives of a number of an equality seeking feminist organizations on a project. When time came for general discussion on the project the workshop was held in an inaccessible location. This meant access to the building was through a back door, which was not wide enough to allow wheelchair entry. A number of the participants took part in the subsequent demonstration. During one of the group interview sessions we discussed this event at length and how some of us felt guilty protesting a group representing women. We asked ourselves why the event was held in such a location but we did not strategize ways to prevent it from happening again.

Why would a feminist group hold such an event in a location inaccessible to some women? The accepted image of a good feminist still includes handling paid work, family responsibilities and having plenty of energy left over for political activity in the evenings or weekends. In these circumstances women with chronic illness are likely to find it difficult to participate in feminist movements or to identify themselves as feminists (Wendell, 2001, p. 24). There are several key issues here. First, the term disability is a wide and fluid concept that to date has not been defined in such a way that pleases everyone. Many women with disabilities do not consider themselves chronically ill but many do. The reality is over the span of a lifetime ‘disability’ frequently varies in degrees of wellness. Along with health, are issues of fatigue. Fatigue in this context does not refer to tiredness at the end of the day but rather it presents itself in an array of complexities such as difficulty concentrating or recalling words. Fatigue can be unrelenting as it leaves an individual as tired arising in the morning as she was when she went to bed. For some, fatigue is unremitting whereas for others it comes and goes suddenly without warning. This type of flux may be misconstrued by women without disabilities involved in political movements who often work very long hours. Sometimes, the fatigue experienced by some women with disabilities restricts hours of work or volunteer time which may be misinterpreted as a lack of commitment or even laziness.

Women with disabilities have become proficient asking for all types of communication such as sign language interpreters, Braille, audio tape or large text but we are not as efficient
asking for other types of disability related supports. Often, we do not speak as loudly about inaccessible buildings or bathrooms and ‘back door’ entrances. Yet it is barriers such as these that prevent us from becoming fully included into women’s organizations. Within St. John’s there are feminist organizations that are still physically inaccessible to some women. One provincial organization has a rear entrance that leads to the downstairs area yet formal meetings take place upstairs. Some women may argue partial access is better than none while others would claim only front door complete public accessibility is acceptable. Whatever one’s point of view that such barriers exist speaks volumes to the exclusion of women with disabilities within feminist organizations. Lack of challenge to both the disability and feminist movements on these issues is directly related to the displaced position women with disabilities hold within these movements.

1 (c) Finding Voice

Institutions such as a university and the ILRC have political platforms from which voice can be projected. Women with disabilities, as marginalized individuals this space is not necessarily available to them as individuals. Making room for women’s voice is a first step towards inclusion. Projection of voice is the essential first step toward affirming human rights (Rioux, 2001).

In 1902, Cooley termed the phrase the ‘looking glass self’. This suggests that one can learn about the self by looking into the eyes of others. The approval or disapproval mirrored back influences our self-esteem. It is not so much the actual physical and/or mental disability that marginalizes women but rather societal influences such as the ‘looking glass self’ that reflects back to person with disabilities societal, cultural, political, physical and emotional influences. Nosek et al state, “… analysis indicated that the women with disabilities had significantly lower self-cognition and self-esteem, and greater social isolation than the women without disabilities…” (p. 1737). Where does this low self esteem originate?

Some participants spoke of childhood experiences that contributed to low self esteem and social isolation. One participant stated, “…doctors say she’s got nothing to do with her life… nothing there for her at all. So, when I was 16, I was made to quit school because there was nothing there for me”. In these sentences this participant described doctors and educators
who failed to see her worth. Her statement speaks briefly to the pervasiveness of systems and how one opinion may be mirrored in other systems throughout life. This participant was never asked what she wanted to do with her life but rather she disclosed a life long history of others telling her what she could and could not do.

However, the impact of these words had a considerable impact when read and reread again in transcripts. We felt the impact strongly upon reviewing transcripts perhaps more so than during the group interview sessions. Indeed there was little collateral conversation as the woman speaks. Why is this? Was this a lack of facilitator experience or was there a more hidden reason? It is not clear why this is so but perhaps it is because some of us did not want to acknowledge the truth of this woman’s experiences. Perhaps we want to believe we have more control.

On reading drafts to this report one participant commented:

I remember these statements and for me my silence was due to reflecting back on the many times I tried to figure out why – through all my hard work I still did not fit in to the mainstream educational experience. Teachers would meet with my mother every year and the same views were shared. ‘Due to your daughters’ special needs’ we feel we are not fully prepared to help her… These comments did not make things easier and just made the experience more isolating and most importantly, silenced my own voice and my search for equity and equality in my all girls’ school. Why continue in school when the adults tell you essentially, you are too much trouble, and you don’t belong here. For many of us all we need is continuous comments like that and continuous reinforcements from others in positions of power to truly silence us from each other and the gifts we all have to share. If my mom didn’t fight for me to stay in school every year, I would be where my fellow participant is.

Some of us developed disabilities after established careers. We heard what some were saying but we do not know how much the school years influenced the self-esteem of women who were told they were worthless on a regular basis. These participants shared their private experiences so that others may gain insight into the invisible powers that have structured their lives. It was through the process of listening to and valuing the diversity of experience that women may be guided to a personal position of power whereby she feels able to produce her voice (Reid, 2002). As participants reviewed the final draft, many commented on this
section. Another woman stated she too was personally disturbed when the woman described
dismal labels that followed her throughout her life. She reflected on her silence and stated
she feared the words the woman spoke. In this particular discussion, silence was speaking
volumes. But labels and fear did not silence the women. The conversation continued.

Another participant stated, “I went to [names school] school as well and they didn’t accept
disabilities, basically.” Another says “In grade nine I was told in front of my whole class that
the only thing I could wish for in life was to be barefoot and pregnant in the kitchen because
there was no other use for me”. These statements reflect a history of oppression from
educational, religious and medical systems. Society has permitted medical, educational and
religious leaders to project these attitudes. The pervasiveness is that the other children in
these classrooms hear from the lips of revered professionals (social authorities) that women
with disabilities have little value.

Cultural and societal rejection of the concept of disability is in part due to the importance
society places on medicine. Zola (1982) suggests the industrial world’s search for cure of all
disease and illness places those of us with disabilities into the category of ‘failure’, as
opposed to previous eras when such failings would be ‘God’s will’. We represent that which
cannot be cured. He claims this failure, when seen by the healthy, produces a ‘thank
goodness it’s not me’ response. After this response the healthy might then feel shame for
such thought. This is a chain of reaction that reinforces feelings of marginalization mirrored
back into the eyes of ‘people with disability’.

In summary the purpose of this discussion was to examine the suggestion that individuals
with disabilities should articulate their own problems and participate directly in analysis and
problem solving. This ideal works well with both the goals of PAR and the IL principles. Not
all of us have the same level of social consciousness. Some of us are unfamiliar with issues
outside of those commonly discussed within the boundaries of the disability community and
might find it difficult to articulate a diversity of conversation. For example, one participant in
the group was a single mother with several children. She wanted to discuss employment
challenges specific to her situation. Others in the group stated they felt the issue at hand was
employment and being a single mother had no bearing on this topic. Articulating our own problems is essential, acknowledging that some of us might find it challenging to locate ourselves in a space we do not consciously think about or relate to.

2. **Direct involvement of people with disabilities in the research process facilitates a more accurate and authentic analysis of their social reality.**

Part of taking control in the research process is to encourage participants to take action that will result in change (Balcazar, et al 1998). During group interview sessions we spent considerable time planning what the final document might look like and what would be acceptable to the group. We also discussed dissemination of materials. However once we left the group dynamics it was sometimes more difficult to get participants to verify the ideas presented while in the group.

In response to a particular request asking for participant clarification one reply stated, “Whatever is best for you.” This reply was repeated many times throughout the various correspondences. After a number of such responses we began to ponder the effectiveness of our facilitation of PAR. Is it that we had not met often enough and delved deeply enough into issues to become motivated towards change?

How does one define change? Riger et al (2004) ask a similar question in a discussion of research collaboration between academia and community. They write, “Some research on preventative intervention shows little long-lasting impact once the researchers have gone. What are the markers that serve as the barometer for change?” (p. 236). Is it that the tools to measure change are not always apparent or that the tools are present but not always recognized? One participant states, “and I know we’ve all been affected by this in some way [referring to group interview sessions], for me very positively”. The question now becomes who sets the parameters to determine change. Is this unprompted example of self-professed change sufficient? Change is a key concept that flows throughout the entire PAR. According to researchers change is a fundamental part of the process (Morris, 2000; Balcazar et al 1998; Taylor et al, 2002).
During the first group interview it became apparent why PAR is emergent in nature. Participants, with a few exceptions rejected AT as their answer to gaining full time employment. They described the history of a system so complex and fluid in nature it was difficult to uncover all of the information lying amongst the layers of bureaucracy.

But participants took control of more than the research question. They changed the proposed format of four two-hour sessions and reorganized the group structure. We split the group in half and combined the last two sessions which was to have been two two-hour group meetings into two groups of six participants meeting for five hours each. When it was suggested these will be very long sessions, the response is that two hours are too short. Participants responded that they were just getting their thoughts organized when the local disability transit buses arrived necessitating an end to the sessions. These changes illustrated participants taking control.

Participant authority enabled risk which challenged the ‘social authority’ of the researchers’ plans. Taking a risk produced positive results and participants where able to construct an environment that worked best for them. If women with disabilities lived and worked in environments that enabled them to have control and challenge control it would become apparent there is often more than one ‘right’ way of doing. These types of experiences throughout the research process provided women with choice and control.

3. The process of participatory research can increase awareness among individuals with disabilities about their own resources and strengths.

Life experiences amongst participants are very diverse. One participant states, “I worked fourteen years with the government.” Another participant states, “The jobs I’ve had throughout my life have always been long-term positions.”

Experiences of others are very different. “So when I became 16, I was made to quit school because there was nothing there for me.” When listening to this statement from the comfort of graduate school the impact is immense. This participant continues on to speak of a lifetime of opportunity void of encouragement and support. The sharing of such personal
information permitted a brief glimpse into widespread discrimination experienced by some women. It is difficult to fully articulate the power of this speech.

In a separate discussion one participant with a non visible disability says

… I’d gotten through my whole life managed to pass but I didn’t know how to read and write. Relationships were very difficult for me because of the same types of labels that were applied to me when I was younger. I was abused (pause) physically sexually and emotionally (pause) in different relationships. And I would like to say that because I think that’s something women with disabilities find it very difficult to talk about because often times we are victims of violence and I’d like to get it in there because I think it’s important for your research.

This participant was correct. Some other members of the group expressed discomfort discussing the topic of sexual assault and initially failed to understand how such events impacted the woman throughout their entire life. We discussed the topic of sexual abuse in a subsequent group session and spoke generally about how it is well documented particularly in relation to some disabilities. It was not a conversation with which we continued.

There is a mutual awareness expressed that as women with disabilities we come from a diversity of backgrounds and hearing the stories of others had varying impacts. A participant writes “…Thank you for this opportunity. It has indeed been quite a revelation for me, and I feel humbled and more appreciative of my own life and the opportunities I have been given.” Several issues of difference we seemed to embrace others we seem to reject. It seems we, as a group of women at the very least have listened to the experiences of others. As a result most expressed lasting impressions about the inner strength of us and our peers.

4. The ultimate goal of the research endeavor is to improve the quality of life for individuals with disabilities.

Oppression is about who has the power and the control and who does not. Charlton (1998) writes, “Oppression occurs when individuals are systemically subjected to political, economic, cultural or social degradation because they belong to a social group.” (p.8). Disability oppression is complex and often only a part of other existing oppressions, such as
gender, race or sexuality which one might experience. Control means to gain power over one’s life. This is one goal of the IL philosophy as well. But how do we, women with disabilities achieve this goal? Many seem conditioned to believe the answers lay within the ILRC, the disability community, or the academics, rather than within us.

During one group interview session we again glimpsed back in time when some women with disabilities held a protest demonstration during an inaccessible women’s gathering. One participant states, “that was a bunch of individuals. I don’t feel the (disability centre) did that.” This was followed by discussion as to whether we were picketing as women or as representatives of an organization. The question now becomes who represents general interests and who represents the personal interests of women with disabilities? The problem with this approach was that it reflected focus from the original issue. The problem is not who will represent but rather that it is exclusionary not to include all women during a feminist gathering.

Is it that participants in this project have come to rely on disability organizations to react to issues that need to be addressed? Or is there a larger picture? Does the problem lie in our own lack of desire to speak for ourselves? Have we, people with disabilities become dependent on organizations and expect them to speak for us? How do we expect to gain a better quality to our lives if we depend on others to address issues only we know about? This trend was seen frequently throughout the project.

For example when we spoke of ways to promote AT in our community, the responses included lists for the researchers to carry out. The sense ‘we’ can do this was not there for most participants. It was possible one reason for this is that participants did not share enthusiasm for the project. In a discussion about this with another member of the research team, the person reported the same observations beyond the confines of this project.

And then came another interview session with a participant. She made a similar comment. She states,

When I was only in my 20’s, I had a lot of energy. …it’s very draining and you just feel like you’re beating your head against a brick wall. … The
concerns are still the same, access, housing and so on ... It’s like a new language and you’re saying the same thing, but in a new way. ... it’s just hard because... that younger crowd. They don’t get it. They don’t know what we’re about. And we can only carry a torch for so long. They got to pick it up. And it’s just not the same. And you’re beating your head against the wall!

What is happening here? Self help and self determination are the key and most radical concepts of the Disability Rights Movement (DRM). These key concepts are primary challenges to our patriarchal western social structure because they enable people with disabilities to take control of their own lives. People with disabilities since the early days of the 1980’s have challenged the whole social concept of the word ‘disability’ but the work is nowhere near complete. “As a practical matter, self help and self determination are illusory short-term goals but extremely important and powerful demands” (Charlton, 1998, p. 128).

It is not that the principles of self help and self determination are not essential but rather that they are two essential tools within a larger workshop necessary to resist the often masked identity of oppression.

Self help and self determination represents two elemental utensils that sanction change. Achieving higher levels of social conscience does not eliminate overall societal oppression as it has no one identifiable form and is omnipresent. The pervasiveness of oppression necessitates that people with disabilities must continuously and methodically chip away at the challenges. Part of the chipping away is developing and maintaining authoritative voices so that we may be represented socially and politically (Viachou-Balafouti, 2001).

So the question of improved quality of life speaks to the impact of the value of the lived experience. The ideal is not about debt reduction or retiring the wheelchair or whatever one presumes the subjective term ‘quality of life’ to mean’. Rather it is about developing a political consciousness that will begin the process of authorizing the ‘disabled’ voice. This will happen through the acknowledgement that the lived experience does formulate ‘experts’ and this expertise is a valuable resource for any society. Social and political authority is learned. Women with disabilities through the lived experience, research and other processes must command ownership of these authorities. This will enhance the quality of women’s lives.
Summary

PAR is linked to ideals. Some of these ideals seem to work well within the paradigms of disability research and some seem to conflict within apparent and unapparent realities that come attached with the concept of ‘disability’. Throughout this project, lived experiences, suggestions from the disability community, input from research partners, information gained from community interviews and informal organizing sessions with interested women within the community have enabled a start towards much needed discussions. Broad community and academic discussion, examination of academic literature and government reports, and reflection of the lived experience each contributes to the growth of action research. Fiscal realities and relations of power challenge the pace of change (thus improved quality of life?) that might be gained from research projects.

Research Design

This PAR is a qualitative type of research that invited women with disabilities to an opportunity to express and record their lived experiences about employment, unemployment, underemployment and AT. There is value in gathering and describing one’s own experiences within the company of others who may have similar yet different experiences. Understanding those experiences is vital.

Thomas states, “understanding experience offers a route through to theorizing the wider social position of women, and thus laying the foundations for politically confronting their own social oppression” (2001, p.530). Gaining voice is an essential first step toward affirming human rights.

The philosophy of this research is to include participants throughout all of the research process to promote a closer reflection of their voice. This is a major shift in research method because theoretically power becomes shared between the entire research team especially the participants.
Participant Selection and Informed Consent

Information about this research project was widely distributed through the ILRC membership and to other disability organizations, equality seeking groups and some disability service providers through faxes, emailing and web site advertising. Individuals who were interested in participating in the research completed an Application to Participate form (Appendix A) and returned it to the ILRC or the PI.

Selection was designed to be purposive however, women challenged their right to decide if they would participate or not. A very diverse group indicated interest in the project and because of this diversity and participant interest all 12 women were selected to participate. Women also challenged the concept of ‘work’ or ‘employment’ described on the Application to Participate Form. Some felt they contributed to society in the form of unpaid or volunteer work. Thus definition of work was not limited to traditional paid employment.

Each person who completed and returned the application to participate (Appendix A) was contacted by phone and the project was explained. The consent to participate (Appendix A) was reviewed in detail. Consent to participate was reviewed again and signed during the first group interview session. Original copies were kept by the PI and store in a locked container and a copy of her consent was given to each participant. Upon request women were provided consents in other formats.

Data Collection

On September 13, 2004 the Interdisciplinary Committee on Ethics in Human Research (ICEHR), MUN granted full approval for the conduct of research in accordance to the proposal submitted. Once this approval and funding dollars were obtained we were free to begin to recruit participants.
When determining the best method of data collection we considered two possibilities, the personal interview or the group interview sessions. Advantages to the personal interview would be increased privacy and possibly a greater opportunity to obtain a fuller picture of each woman interviewed (Oakley, 1981). It was determined however, that group interview sessions offered the flexibility of shared disability supports.

Group interview sessions also called focus group sessions were chosen as an affordable means of data collection. Group interviews happened when women gathered and took part in focused discussion. Originally we scheduled three two-hour group interview sessions and an AT workshop. Participants decided to change this plan. We met for the first two-hour group interview. The next week we met for an AT workshop, which was held at the ILRC. Both of these two gatherings took place within two weeks of a busy winter holiday and eleven of the twelve participants were able to attend. Several weeks later the larger group was divided into two sub groups. Participants gathered for one of the two five-hour group interview sessions. All of these sessions were held at the ILRC during weekends or holidays. Meetings provided not only research data but also an opportunity to gather and share experiences, to network with other women, and to hear of the life experiences of others.

A central feature of the study was the AT seminar/workshop. This workshop was designed to share information about the latest AT equipment available through hands on demonstration of multiple pieces of hardware and software. The demonstration was given by an ILRC staff person. A large amount of AT was donated to the group by a local AT company Compusult. Equipment was demonstrated, tried out, and discussed in relation to cost and availability. Some women did arrange follow up appointments with the ILRC staff person to obtain more information about AT.

Multiple forms of data collection were believed to enhance researcher understanding of complex issues. Reinharz states that; “feminist researchers combine many methods so as to cast their net as widely as possible in the search for understanding critical issues in women’s lives. The multi method approach increases the likelihood that these researchers will understand what they are studying, and that they will be able to persuade others of the
veracity of their findings” (1992, p. 2001). Other sources of data include researcher field notes, tape-recorded group and personal interviews and e-mail correspondence. Personal follow-ups to the group interview sessions would have been ideal but this was not an option. One individual, unable to attend a longer session requested a personal interview. This interview was both informative and dynamic but it may lack the interaction of other points of view.

Any quotes from participants from personal correspondence (email) with the PI were granted permission to be included in this report. Other personal reflections came from a field notes diary kept by the PI since the project began. Participants rejected the use of pseudonyms and stated they preferred general use of the word participant. While a repetitive term, women stated it enabled a greater degree of anonymity. The word participant denoted the active role participants took in influencing all aspects of the research process including this report.

Initially we had planned to involve people from the community to form a research advisory committee. The committee was proposed to collaborate with the PI and co-investigators (Co-Is) in developing the details of the research plan. However, this committee was not formed. Following a meeting with some women with disabilities who gathered in a consultative capacity to help with the structure of the research and to ensure it reflected the values of the IL principles we cancelled this plan. The women felt strongly that such a committee might create an ‘us’ and ‘them’ approach. The fear was that the experiences expressed by participants might conflict with the opinions of the committee. We agreed such potential might be possible and stopped these plans. However, in an effort to gain more of an understanding of some of the government, educational and community disability support systems of which the women spoke, some of the researchers visited a number of agencies and talked to individuals who work with persons with disabilities. These informal and unrecorded discussions enabled a greater comprehension of some disability services and how they do and do not work to meet the needs of women with disabilities.

The principal investigator (PI) and research assistant (RA) attended all focus group sessions. The PI recorded flip chart notes and operated the tape recorder. The RA took hand notes
including facial expressions and actions that might not have been reflected on the tapes. The personal interview took place in the participant’s home. This session was recorded. All tapes and notes have been secured in a box and the only PI, RA and Dr. Gustafson would be permitted access to the transcripts and/or tapes. After seven years the PI will shred or destroy all data collected.

**Data Analysis**

The Canadian Research Institute for the Advancement of Women or CRIAW discusses PAR as a method of research whereby study participants are both the subjects of the research as well as the researchers (Morris, 2002). Reflection of one’s experiences holds the potential to provide women with a greater understanding of themselves and others around them. Reid states; “integral to a feminist action research design is the acknowledgement and acceptance of multiple realities of women’s lives as well as valuing the shared creation of data between researcher and participants” (2002, p.173). It is essential that each participant be guided to a personal position of power whereby she feels able to produce her voice.

Experiential knowledge is brought to the research process when participants can articulate their issues and concerns, assist in development of materials, and participate in the process of facilitating change. PAR also mandates a respectful and collaborative approach to planning, execution, and evaluation of results by participants. Because of the nature of PAR data collection, analysis, and dissemination were emergent and fluid processes.

Transcripts of data collected during group interview sessions have been provided to all participants in their format of choice. Participants were given revised personal copies of their own data only. Transcripts were then examined for common threads. Dialogue, revisions and more revisions happened all throughout the data collection and analysis process. Participants and co-investigators were offered opportunities to revise portions of the document as each piece was written. All of the research team was provided a final draft copy to revise. We met
as a group and individually to discuss the final draft, what we liked and what we did not like and to revise the report draft. We aimed for consensus on issues of disagreement.

We devised a plan to disseminate the final report and provided opportunity for all involved in the research to provide input. There are three report styles; a summary report, a full report and a CD report. The 24 page Summary Report booklet has pictures and a tactile image. This full length report is a more academic text. Both the Summary Report and this full Report are available on CD. Time and lack of funding prevented the full report document from being available in Plain Language. Participants aware of these restrictions supported a Summary Plain Language report. This is a compromise rather than a choice. In an effort to include all participants the CD will offer various text and Braille versions. Text versions offer the opportunity for a person to use a voice reader. This report will be uploaded to our accessible web site.

**Tactile Medium – A Symbol of Inclusion**

We acknowledge that there is more than one way to ‘read’ information. As a symbol of diversity and inclusion, this report featured tactile medium. This is paper with our print logo that has been heat-processed. The heat raises the dark sections of the image so that it can be distinguished by touch. This tactile of the project logo consists of a universal female symbol (a circle joined to a T). Inside the circle is a computer representing one kind of AT. When one of the participants was given a logo as a ‘test of effectiveness’ she was unable to identify the universal female sign. Rather perplexed by our failure and after some questioning we realized the participant had no concept in her mind as to what the universal woman symbol might look like.
Research Limitations

The following represent identified limitations to research:

1. Barriers to anonymity
2. Fear of repercussions
3. Homogeneity of voice

Barriers to anonymity

Within a small gathering of women, acknowledging the distinctiveness of some disabilities and considering the small core group from which the selection process originated it is unrealistic to guarantee and maintain total anonymity for participants. This issue was discussed during group interview sessions and at the point in time when participants were offered drafts to read.

Participants chose how they wished to have their voice heard. Methods discussed to disguise identity were use of a pseudonym or code system or the generalized application of the word participant, or any combination of the two. The majority of participants replied that they felt the general use of the word participant would provide them the most anonymity.

Fear of repercussions

Drafts were offered for participant review even at very early writing stages. Several participants expressed fear their remarks would lead to problems dealing within disability-related systems in future. “… I put myself at risk disclosing my own experiences”. “I think its really good to have a face, have faces to it, but there has been some things said that may in fact it needs to be said but yet I’m wondering what [about] the ramifications…” . Such concerns were taken seriously. Pictures included on the CD may or may not include research participants. Pictures have been taken with individual permission and are meant to signify the diversity of women.

Participants have had significant input into the shaping of this document and it is hoped this will minimize participant risk. Effort has been taken in writing style to prevent identification
of participants as much as possible. If a participant feels discussion specifically identified her and she has had the option to have the remark removed.

**Homogeneity of voice**

It is essential we do not project a sense that this document speaks for all the women with disabilities in NL. Haraway cautions the goal of research is not to search for a positivist truth (1988) but rather to gather the individual perspectives of a particular group of women. This report reflects the perspectives of twelve St. John’s women with disabilities who gathered over a period of months acknowledging perspectives were fluid and ever reshaping. Reid states; “integral to a feminist action research design is the acknowledgement and acceptance of multiple realities of women’s lives as well as valuing the shared creation of data between researcher and participants” (2002, p.173). Data collection and analysis was an on-going process that sanctioned participant editing, reflection, and endorsement.

**Participant Profile**

The twelve women who participated in this research were very diverse not only in disability but also in age, work and AT experiences. All but two participants reported daily use of their computer either at work, at home, or in other places. The following is a brief summary of information about participants gathered from the Application to Participate Form (See Appendix A).

**Table 1: Representation of Participants According to Age**

<table>
<thead>
<tr>
<th>Age Range (years)</th>
<th>19-29</th>
<th>30-39</th>
<th>40-49</th>
<th>50-65</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 1 includes only the age of participants because adding other variables may make identification of participants more possible. Anonymity cannot be guaranteed due to the small numbers of women with disability in the St. John’s area. For this reason participant information remained generalized.
Types of disability reported by participants include:

- AIDS related complications
- Blind/Visually impaired
- Chronic Pain
- Developmental
- Learning
- Mobility

One participant was retired from full time employment and now works as a volunteer. Three participants were employed full time, two were working within the disability sector and one was on long-term disability leave. Most other participants were seeking employment or attending post-secondary schooling.

Some women said they had become pessimistic over the years about securing long term paid work. They reported extensive histories of job programs and placements. This experience provided minimal access to secure and sustained labour market with little, if any health care or pension benefits. Some reported employment with little more than a living wage while others reported no employment opportunities. Two participants identified three major career barriers: the extent of their physical disability, their need for work and disability related supports, and the structure of most workplaces. Workplace structure includes not only physical accessibility but as well attitudinal perspectives concerning physical disability. For these two women access to non-traditional paid employment has been elusive.

All women in this study had completed high school or equivalent. While eight women had post secondary education, most had participated in a variety of training activities including technology certificates, and work placements. Many participants recalled participating in a variety of assessments including, intake, skill development, occupational therapy, skills upgrade, and Dress for Success. Participant experience reveals that higher education, vocational training, and workplace experience had not enabled them to overcome other systemic barriers to satisfying, sustained employment.
Participant Technology Profile

Computer Use

The author of *Report on the Use of the Internet in Canadian Women’s Organizations* (1996), Leslie Regan Shade claims factors of income, race, gender and the educational system influence computer inequity. She states women are less likely to be producers, designers or consumers of Internet technology. One of the factors that negate this computer inequity is a higher family income.

More recently Womenspace (2004), an initiative supported through the Voluntary Sector Initiative and Status of Women Canada, researched women and the Internet. A portion of this analysis focused specifically on women with disabilities. Womenspace states, “…women with disabilities face increased barriers of isolation and exclusion in today’s increasingly technologically connected society” (p. 29). Participants identified a number of obstacles that sustain this isolation. Poverty brought on from lack of admission into labour market prevents women with disabilities not only access to AT in the home but within the community as well. Public Internet sites are often not only computer inaccessible but also building inaccessible. Another participant stated accessible sites were of little value to her if she did not have the five dollars necessary to get the public disability transit back and forth to the site. Most participants agreed transportation was an obstacle for them. Another participant stated the expense of childcare makes public Internet access less appealing to her.

In an effort to build a technological profile we asked participants the following questions:

- How often do you use a computer?
- Do you have computer access at home?
- Do you use email? If so how often?
- Do you use public Internet sites?
- What activities would you use the Internet for?
- Do you shop on-line?
All participants report close to a daily use of computers. Ten have access to a computer in the home. Most participants communicated via email regularly throughout this study. Three participants have computer access either at work or through the Canada-Newfoundland and Labrador Community Access Program (CNL-CAP). CNL-CAP is a joint provincial and federal government endeavor designed to provide computer/Internet access to every Canadian. The Independent Living Resource Centre (ILRC) houses an active and fully accessible CAP site.

Ten women used the Internet for a variety of reasons. Three specific uses identified were retrieving information, checking and sending email and performing job searches. One participant states she has Internet access only when she can afford it. Another participant who has a sensory disability affirms for her the Internet is too frustrating to access on a regular basis. One woman uses the computer to read aloud to her children.

One participant states, “I totally, absolutely depend, rely on adaptive technology, especially in employment and through my school.” This participant relies on AT in many areas of her life such as making up a grocery list, reading mail and scanning books. She states it is her primary source of communication.

Eleven of the twelve participants do not shop on-line. Reasons for this varied from distrust of the system to not owning a credit card.

**Adaptive Technology**

Participants were asked about their experience with AT. AT is defined as “computer software and hardware that have been modified to be accessible by people with disabilities, or equipment created to be compensatory tools for people with disabilities” (Cunningham & Coombs, p. 3). According to this definition only a few participants had experience using some AT. Most did not. More interestingly, the participants had their own ideas about what constituted AT. Table 2 depicts information obtained from the Application to Participate form (Appendix A).
Table 2: Participants’ Reported Experiences using Adaptive Technology

<table>
<thead>
<tr>
<th>Participant</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>[I use] “Kurzweil, tape recorder, JAWS, [and] Dragon Dictate or Dragon Naturally Speaking.”</td>
</tr>
<tr>
<td>B</td>
<td>[I use a] “height adjustable desk, [but] little other”</td>
</tr>
<tr>
<td>C</td>
<td>[I use] “very little [adaptive technology]. I don’t know what’s available and what can help make my education and job search easier.”</td>
</tr>
<tr>
<td>D</td>
<td>[I use] “computers with WordPerfect and Microsoft Word, [and no adaptive technology].”</td>
</tr>
<tr>
<td>E</td>
<td>[I use] “wheelchair desks; I know AT [adaptive technology] is available on computers but I’ve never used it before.”</td>
</tr>
<tr>
<td>F</td>
<td>[I do not use adaptive technology] “I am not sure what is out there.”</td>
</tr>
<tr>
<td>G</td>
<td>“I use some adaptive technology like a key guard. I am interested in finding out more – specifically [about] voice activation systems.”</td>
</tr>
<tr>
<td>H</td>
<td>“minimal” [use of adaptive technology]</td>
</tr>
<tr>
<td>I</td>
<td>[I use adaptive technology] “to ease pain on joints, muscles and bones.” [I also use] “voice input system and an ergonomic set up.”</td>
</tr>
<tr>
<td>J</td>
<td>[I volunteer in an] “Canadian-Newfoundland and Labrador Community Assess Program site”</td>
</tr>
<tr>
<td>K</td>
<td>[I use] “technical aids [to help with the computer, as well as] disability options under Windows to assist writing.”</td>
</tr>
<tr>
<td>L</td>
<td>“I use adaptive technology everyday in both my personal and work life. Adaptive technology helps me work, read, communicate, learn, write and note take independently.”</td>
</tr>
</tbody>
</table>
The following findings and recommendations are based on the experiences expressed by women with disabilities who engaged in participatory action research with community partners. The recommendations are aimed at government and non-governmental agencies, educational institutions, employers, and individuals interested in promoting employment and educational advancement for women with disabilities.

**FINDING # 1**

Women with disabilities face numerous obstacles to sustained and satisfying employment. Among the obstacles are difficulty accessing education, transportation, and AT in the workplace as well as the low self-esteem that comes with facing closed doors again and again (ODI, 2003; Bakan and Kobayashi, 2000; Nosek, Hughes, Swedlund, Taylor, and Swank, 2003; Fawcett, 2000). As a result, many women live a cycle of unemployment and underemployment.

One of the solutions adopted by Alberta was to create an Office for Disability Issues. The mandate of this Office is to promote positive attitudes towards disability issues, removal of barriers to government programs and services, and provide a reference point for people with disabilities (ODI, 2002). However, some disability advocates warn this type of system may lack accountability and effectiveness. A 1991 NL study into the feasibility of a Premier’s Council on the Status of Persons with Disabilities recommended a different structure similar to the NL Women’s Policy Office (Boland, 1991; Working Group on the Status of Persons with Disabilities, 1994). This new structure would work across institutions to ensure inclusion and accommodation and would analyze how new and existing policies affect and exclude persons with disabilities.

**Recommendation:**

FINDING # 2

Employment opportunities reported by women with disabilities are alarmingly low even among women with advanced educational preparation. Women want long term jobs that will provide them with benefits and income security. Although the federal and provincial governments acknowledge employment problems experienced by women with disabilities (Federal, Provincial and Territorial Ministers Responsible for Social Service, 2000; ODI, 2004; Department of Human Resources and Employment, Government of Newfoundland and Labrador, 2002) there is no effective action plan for improving employment opportunities.

Recommendation:
- Develop a comprehensive action plan for addressing the employment crisis reported by women with disabilities.

FINDING # 3

A total of 75 Employment Equity and Strategic Initiative jobs in the provincial civil service are designated for people with disabilities. This is insufficient. More jobs must be made available. Some of these must be designated specifically for women with disabilities. It is the responsibility of both levels of government to make this happen.

Recommendation:
- Increase the total number of Employment Equity and Strategic Initiatives jobs in NL and designate some jobs specifically for women with disabilities.

FINDING # 4

Few public or private sector employers have voluntarily implemented employment equity. Memorial University of Newfoundland is one employer that has responded voluntarily to this call.

When members of the disability community ask why women with disabilities are not being hired, few employers have mechanisms in place to explain why jobs are so elusive for this
group. Women feel that neither government nor employers are accountable for explaining why women with disabilities are less able to gain workplace entry.

Recommendations:
- Establish a mechanism for employers to document strategies used to recruit, select, and promote women with disabilities.
- Make accountability reports available upon request to community organizations.

FINDING # 5

Currently, women with disabilities in Newfoundland and Labrador depend on employers’ voluntary participation in employment equity. Voluntary participation has not increased the numbers of employed women with disabilities in this province.

Recommendation:
- Enlist the support of disability organizations, feminist organizations, and other concerned individuals and groups in lobbying the provincial government to legislate employment equity.

FINDING # 6

Participants report that securing full time work under The Employment Equity and Strategic Initiatives can be difficult. Those who have the necessary education and job skills say they still face logistical and financial obstacles relating to transportation and relocation. Women with disabilities, disability community representatives, and those working within government equity initiatives must ensure that the allocated equity jobs are accessible to the designated population.

Recommendations:
- Identify and establish the suitability of designated jobs within Employment Equity and Strategic Initiatives in collaboration with members of the disability community.
- Build into the job program disability related support for transportation and relocation.
FINDING # 7

Employers in NL, many of whom are small businesses, are not equipped to address the unique issues that come with using workplace AT. Women with disabilities want to meet with employers, policy makers, and representatives from disability organizations and other community organizations to discuss the use of workplace AT.

Recommendation:
- *Develop a collaborative community-based approach that puts women with disabilities at the center of the discussion about employment and AT in the workplace.*

FINDING # 8

Processes for accessing disability related support for employment are slow. Women report lost job opportunities because of delays in accessing workplace accommodation. Funders and employers must respond in a timely fashion so that employment opportunities are not lost.

Recommendation:
- * Expedite access to disability related supports required for employment purposes.*

FINDING # 9

AT is linked to government departments rather than to the individual who requires it. This rule limits portability of technology across departments and the possibility of renewed employment for a woman with a disability.

For example, when a woman accepts a short term contractual civil service job, she will receive AT as a disability related support. When her contract ends, so does her access to this AT. Should she apply for a contract in another department, she or her prospective employer must negotiate to have the AT transferred or acquire the same supports in a new department. This lack of portability of AT means that women with a disability can be seen as having an added cost attached to their employment unlike the applicants without disabilities.

Recommendation:
- *Establish a policy that links AT directly to the individual rather than a government department.*
**FINDING # 10**

AT tends to be institutional and unappealing in appearance. Mainstream technology tends to be trendy and appealing to its consumers. This visible difference in the workplace can make users of AT feel less deserving as workers and consumers. Women with disabilities want to be treated as consumers deserving of similar attention to buyer appeal. More appealing AT may promote wider use and acceptability by women with disabilities and those who work with and employ them.

**Recommendations:**

- *Establish accessible mechanisms for consumer feedback about AT*
- *Educate manufacturers of AT that appearance and function are important to this consumer group.*

**FINDING # 11**

The Canada Newfoundland and Labrador Community Access Program at the Independent Living Resource Centre in St. John’s is a Centre of Excellence in AT. With the exception of the ones located in Industry Canada’s community access program sites, few public internet sites offer AT. Moreover these sites do not have on-site staff who are fluent in AT and able to expand and maintain the equipment and offer training to potential users.

**Recommendations:**

- *Ensure continued funding of the Centre for Excellence in AT at the Independent Living Resource Centre in St. John’s, NL.*
- *Evaluate the strengths and areas for improvement of all provincial community access program sites with a view to improving access to adaptive technologies.*
- *Use the results of the evaluation to justify improved funding for AT and resource personnel for all provincial community access program sites using the St. John’s site as a model for excellence.*
FINDING # 12

AT is a disability related support. Therefore it should be exempt from tax as are other forms of disability related supports.

Recommendations:
- Recognize AT as a tax exempt disability related support.
- Provide tax rebates for disability related supports not covered by health insurance.

FINDING # 13

Initially, certain adaptive technologies were designed to accommodate the needs of those with specific disabilities. Funders of AT categorized disability related supports according to the type of disability for which they were initially designed. Over time, these technologies have proven useful to a wider range of users. However, the classification system has not evolved to reflect this wider use. Therefore, some women with disabilities do not have access to the full range of adaptive technologies.

Recommendation:
- Revise the current categorization of AT by disability to reflect broader suitability and usage.

FINDING # 14

AT has the potential to transform the employment and educational experiences of all women with disabilities. Some women with disabilities question the value of AT in facilitating workplace entry. For them, AT adds to the perception that disability is about being needy or deficient. One participant puts it this way. “From an employer’s perspective, they see one person who needs AT versus another person who doesn’t. Who are they going to hire?”

Recommendations:
- Promote public awareness by initiating a media campaign that educates all Canadians about the value of AT.
- Create widespread educational directive that enables women with disabilities the opportunity to become fully informed about AT.
- Fund a position at the fully accessible Canada-Newfoundland and Labrador Community Access Program in the Independent Living Resource Centre in St. John’s, NL to identify and disseminate information about the value of AT.
FINDING # 15

Education is associated with better health and a higher standard of living. Women with disabilities report physical, structural, and attitudinal barriers to equitable access to higher educational institutions and programs in NL. Students also have a responsibility to ensure they receive the supports they require within educational experience. Participating in post secondary education must be supported by an institutional structure which allows them to assume some responsibility and challenge inaccessibility issues.

Recommendations:

- Establish formal links between educational administrators and women with disabilities to identify site-specific barriers and solutions to improve access to institutions and programs.
- Support the development of formal and informal mechanisms for students with disabilities to raise accessibility issues within their institutional settings.

FINDING # 16

Women report that the application form for the Canada Study Grants for Students with Disability is difficult to complete and appears to be aimed at youth living at home. The form asks for the names and addresses of parents which is inappropriate for mature students. The application form asks for proof of “need of one dollar”. Women do not know how to demonstrate this type of need. Moreover, women do not know if receiving these funds will jeopardize their status with other programs. Some say that it is safer not to take the risk of applying for a student grant. This grant must be re-examined for all of these reasons.

Recommendation:

- Examine the application process for the Canada Study Grants for Students with Disability.
FINDING # 17

Some women with disabilities do not have a well formed plan for making the transition from the better supported environment of education to the less supported environments of employment in the private and public sectors. Startling gaps in support for career planning is due in part to the structure of some systems. For example, some women reported having to return computers and other AT to a funding agency after completing their education. Funding agencies regard AT as temporary methods of coping with education and not as necessary supports for women making the transition to employment. Thus AT is tied to a specific site or institution rather than to the individual as she moves from one site to the next.

Recommendations:

- Reassess funding guidelines for AT to allow for the portability of equipment as women transition from an educational setting to a workplace setting.
- Educate those working in the offices for career development at educational institutions about the value of AT in making a timely transition from education to employment.
- Fund research to investigate career planning mechanisms for women with disabilities.
- Provide information sessions to women with disabilities (prior to beginning post secondary education) about the type of employment opportunities available to them through Employment Equity and Strategic Initiatives.

FINDING # 18

Just like other members of society, there are a variety of health and personal reasons why some women with disabilities are not able to seek or hold employment at any given time. Computers and other AT have many applications that enhance women’s personal lives such as reading, communication, organizing daily tasks, and accessing current information. Maintaining computer skills is especially important to women when they are ready to reenter the workforce. However, few women with disabilities have incomes that enable them to get and maintain AT for personal home use. The cost of transportation and child care limits access to technologies in public spaces such as libraries and the Canada Newfoundland and Labrador Community Access Program.

Recommendation:

- Establish mechanisms for improving access to AT for personal use and career development of women with disabilities.
SECTION 5: SUMMARY

“Hopefully one day I’ll make enough money that I won’t have to do anything with systems”

Academic literature and government reports clearly document that women with disabilities face significant obstacles to labour market entry. One often cited response to these issues is to provide access to AT for women with disabilities. The problem however, appears much more complex.

Participants in this study denied their need for AT. Initially this denial appears puzzling but upon closer reflection such reactions are understandable. First, there is little policy that supports access to AT use in the workplace, maintenance of equipment, or portability of equipment. Second unemployed or underemployed women have little financial capacity to purchase and maintain their own AT and computer equipment. Third, this combination of the lack of policy and equipment does not build an employment environment that adequately supports women with disabilities. For many women with disabilities AT signified another ‘need’ to be negotiated with reluctant employers.

Lack of employment equity legislation is another problem. The assumption that initiatives will be taken by employers because it is ‘the right thing to do’ is not working. Little has been done by private and public sector employers to address the serious employment problems faced by women with disabilities. Research reports and government statistics indicate that women with disabilities in Canada are not active participants in the labour market.

Dissociation from other lobby groups or feminist organizations impedes the development of lobbying expertise by women with disabilities. Lack of accessible buildings and meeting places and a general disengagement in feminist issues reinforces many women’s experiences of isolation. Resistance on behalf of women and feminist organizations to address this disconnection also contributes to the marginalization.

We have recommended that a formal mechanism be funded that addresses issues specific to all people with disabilities. There is some disagreement about what that mechanism should
look like. Some community leaders claim development of a bureaucratic structure would serve to locate people with disabilities further from the political arena. Historically the efficiency of many such structures in other areas of Canada has lacked accountability and effectiveness. Other community leaders suggest a formal mechanism grounded in disability issues could provide a venue that enhances political understanding. These leaders say it is worth the risk and one method to increase public awareness of disability issues.

Disability related supports at the organizational level do not facilitate a smooth transition from education to employment. Part of the problem is that AT is viewed as a temporary method to entry into education rather than a long term solution to inclusion in all facets of society. This is one underlying problem that was consistent throughout the research. AT which facilitates accessibility to a workplace is not “attached” to an individual in the same sense as a wheelchair. Both perform a similar function by increasing social mobility and access. Yet, AT is viewed as an unrelated funding requirement rather than a technological advancement that holds the potential to even the playing field for all citizens.

Women note that great gains have been made in regard to education. While not every participant has had access to the level of education she desires, most have. There are many reasons women seek post secondary education, for some it is to improve their chances of finding a career in an area of their interest. For others the education experience is a way to keep occupied, to meet new people, to learn new perspectives and a pathway to explore new life experiences.

Women also take some comfort reading government reports that do articulate some of the concerns they experience first hand. Women want change and it is not always clear how change may be achieved. It is time to invest the policies with substantive meaning that will translate into more changes in women’s lives.

In summary, attitudes must change for women with disabilities to gain full citizenship in Canadian society. Without immediate action on the recommendations of this report, AT will remain only a concept rather than a substantial and effective mechanism of inclusion.
REFERENCES


Invitation and Information for Research Participants

*ALTERNATE FORMAT AVAILABLE.
Closing DATE for Applications: Nov 29, 2004

This is an invitation to participate in a research study. This study will bring together 10-12 women with disabilities who are interested in sharing their feelings, beliefs, about employment, education, and training in relation to Adaptive Technology (AT). AT is computer hardware and software that enables an individual with a disability to effectively use a computer. AT does not have to be technical; it may as simple as a height adjustable workstation.

My name is Michelle Murdoch and I am a woman with a disability. I volunteer at the Independent Living Resource Centre (ILRC), which provides services for people with disabilities. I am also a graduate student enrolled in the Women’s Studies Masters Program at Memorial University. Collaborators in this study are my academic supervisor at MUN, Diana Gustafson, and Executive Director of the ILRC, Barry Galloway.

I would like to hear from women with different types of disabilities, of all ages, ethnicities, employment experiences, and skills using AT. If you are a woman who is currently working, seeking employment, attending a post secondary institution, or enrolled in a training program, please fill in the attached form or contact me directly. Contact information is below.

The research team will select 10–12 participants from those who indicate their interest by completing the attached form. Not everyone who wants to participate can be included in this study because it is not practical to have a larger group given study objectives. Participant select will be as diverse as possible. Diverse refers to various kinds of disabilities, ages, work experience, and knowledge of Adaptive (or Assistive) Technology. No one will be discriminated against because of disability, race, or sexual orientation.

This study may benefit you by giving you an opportunity to:
1. Share your knowledge about disability, employment, unemployment, and AT with other women with disabilities.
2. Attend a workshop about AT.
3. Contribute to positive change by communicating shared experiences with government agencies, community organizations, and potential employers in St. John’s and across Canada.
Selected participants will collectively decide what they want employers, educational institutions, and governments to know about women with disabilities, AT, employment or unemployment. All issues about how to gather, analyze, and communicate data will be discussed in the group before deciding how to proceed. Everyone’s opinion is valuable and will be respected.

Tentatively, the plan is to join me in three 2-hour focus groups and one 2-hour AT workshop. Group meetings will take place at the ILRC. These focus group meetings will be tape-recorded and/or recorded by a note-taker to ensure an accurate record of your comments and opinions. Participants will have an opportunity to read a copy of what they say (transcript) and may make changes, additions, and deletions to their own comments. The typist, my university supervisor, and I are the only other people who will read these transcripts. The audiotapes, notes, and transcripts will be kept in locked storage when not in use and will be destroyed seven years after completion of the project.

Participants will have the option of deciding whether they wish to remain anonymous. All participants will be required to keep confidential all discussions that take place during this study.

Participants will receive reimbursement for transportation to a maximum of $5.00 or each round trip. Participants who incur childcare expenses while attending the focus groups and workshops will be reimbursed at $6.00/hr to a maximum of 8 hours. Alternate formatting costs will be provided for study participants. Accommodations such as attendant (helper) care will not be covered.

A summary report of the information gathered in this study will be shared by the Canadian Center on Disability Studies. Each participant will receive a copy of the final report. The report will also be distributed to governments, community organizations, and interested employers. A copy will be posted on Memorial University and ILRC websites. Information gathered from this study may also be used in the preparation of scholarly papers or conference presentations.

If you have, any questions about this please contact:
Michelle Murdoch at 722-4031 (leave a message) or by email mmurdoch@nl.rogers.com
Dr. Diana L. Gustafson at 777-6720 or by email at Diana.Gustafson@med.mun.ca
Barry Galloway at 722-4031 or by email barry@ilrc.nf.ca

The proposal for this research has been granted full approval by the by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about the research you may contact the Chairperson of the ICEHR at ice@mun.ca or by telephone at 737-8368.

*ALTERNATE FORMAT AVAILABLE.
THANK YOU & I HOPE YOU AGREE TO PARTICIPATE!
Application to Participate

PLEASE READ THE INFORMATION SHEET BEFORE COMPLETING THIS FORM.

**** ALTERNATE FORMATTING IS AVAILABLE UPON REQUEST.

We are trying to bring together women of all ages with different types of disabilities, and varying work and education experiences. The following questions will help us in selecting a diverse group of participants. You do not have to answer any of these questions if you do not wish to.

When you have completed the form, please leave it in the envelope provided at the reception desk of the ILRC, or email the information to me at the email address listed below. Alternate format accepted, just arrange through the ILRC. Forms may also be mailed directly to the ILRC. Please address the envelope Attention: Michelle Murdoch.

Yes, I am interested in participating in the research study called, Women with Disabilities and Adaptive Technology in the Workplace: Participatory Action Research and Applied Principles of Independent Living

Name _____________________________________________________________________

Address_______________________________________________ _______________________

Contact Number ____________________ E-mail __________________________________

I identify my disability as _____________________________________________________

If I am selected, my preferred format of communication is:

__________________________________________________________________________

My experience using Adaptive Technology is ________________________________

__________________________________________________________________________

__________________________________________________________________________
This best describes my work experience at present: (check as many as apply)

- I am presently working
- I am attending a training program
- I am attending post secondary institution
- I am currently looking for work
- I have become discouraged in my effort to find work and am not currently looking for work
- Other (please describe)

I am in this age range (check one)

- 19-29 years
- 30-39 years
- 40-49 years
- 50-65 years

Please check one:

- I will require child care
- I will not require childcare

I have had the following types of jobs or education or training in the past five years. (Include any AT training you have had.)

THANK YOU FOR YOUR INTEREST

I will notify you if you are selected to participate in this study by (date TBA).

If you have any questions about this study please contact:

Michelle Murdoch by email mmurdoch@nl.rogers.com
Dr. Diana L. Gustafson at 777-6720 or by email at Diana.Gustafson@med.mun.ca.
Barry Galloway at 722-4031 or by email barry@ilrc.nf.ca.

Or leave a message in your desired format at the ILRC 722-4031. Thank you.

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about the research you may contact the Chairperson of the ICEHR at ice@mun.ca or by telephone at 737-8368.
Consent To Participate

Title of Study: Women with Disabilities and Adaptive Technology in the Workplace: Participatory Action Research and Applied Principles of Independent Living

Name of Participant: (please print)____________________________________________

I understand that the study in which I am agreeing to participate involves sharing my feelings and beliefs, about employment, education, and training in relation to Adaptive Technology (AT). A group of 10-12 women with disabilities will meet for three 2-hour focus groups and one 2-hour AT workshop.

I know all information pertaining to this study can be made available in alternate formats. I must self-identify my need for an alternate format.

I understand participation in this study is voluntary. I may withdraw from the study at any time, regardless of the reason and without prejudice.

I understand that participants will work as a group deciding what we want others such as employers, educational institutions, and governments to know about women with disabilities, AT, employment or unemployment.

I understand I will have the option of deciding if and how I will be identified or if I want to remain anonymous.

I understand that I am under no obligation to answer any question that I do not wish to answer.

I understand that information sharing within the group will be recorded on audiotape and in handwritten notes.

I understand conversations between participants that occur during this study will be confidential and not discussed outside the group.

I understand I will be reimbursed for transportation to a maximum of $5.00 for each workshop or focus group meeting I attend.

I understand that childcare expenses I incur while attending the workshop or focus group meeting will be reimbursed at $6/hr to a maximum of 8 hours.

I understand all alternate formatting is available free of charge and upon request. I understand I will not be reimbursed for other forms of accommodation such as attendant care that I incur while attending the workshop or focus group meetings.
I understand only Michelle Murdoch her academic supervisor Diana Gustafson, and a typist (to be determined) will have access to the original research study material.

I understand I will have an opportunity to review a copy of the audiotape transcript and notes taken during focus group meetings so that I can make changes, additions, and deletions to my own-recorded comments.

I understand I will have the opportunity to discuss and contribute to the analysis of study findings when the final draft is completed.

I understand that the information obtained from the focus groups and workshops and any other information sources deemed necessary by the participants will be used for the specified study and potential publication(s) arising from it. Information gathered from this study may also be used in the preparation of scholarly papers or conference presentations.

I understand all original data obtained from the focus groups, workshop, or other information sources identified by the participants will be shredded or erased at the end of seven years.

I understand Canadian Council on Disability Studies (CCDS) will receive a summary report of the information gathered in this study. This report will be distributed to governments, community organizations, and interested employers. A copy will be posted on Memorial University and ILRC websites.

Participant Signature: ________________________________ Date____________________

I have explained as fully as I can the purpose and procedures of this study to the above volunteer. I have sought questions and I have answered any questions openly and honestly.

Researcher Signature________________________________ Date____________________

Thank you for agreeing to participate!
Consent forms are available in alternate format. Please inform me of the format you prefer. You will be provided a copy of this form for your future reference.

If you have, any questions about this please contact:
Michelle Murdoch at 722-7937 or by email mmurdoch@nl.rogers.com
Dr. Diana L. Gustafson at 777-6720 or by email at Diana.Gustafson@med.mun.ca
Barry Galloway at 722-4031 or by email barry@ilrc.nf.ca

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University. If you have ethical concerns about the research you may contact the Chairperson of the ICEHR at ice@mun.ca or by telephone at 737-8368.