Surviving the Shift: Exploring the Use of Information and Communication Technologies (ICTs) by Community Development Organizations of People with Disabilities in the Knowledge-Based Economy

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Toward the completion of an Interdisciplinary Master's Degree in Disability Studies at the University of Manitoba

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Abstract

With the shift toward what many have called a 'knowledge-based economy' new technologies or Information and Communication Technologies (ICTs), like computers and the Internet, have increased their importance to those wishing to participate in social, political and economic life. Organizations of people with disabilities embraced these technologies as having the potential to make their jobs easier. And while in some cases, the real potential of technology has exceeded their expectations, the use of technology has added new issues and concerns to the organizations' agendas.

This thesis research consists of three case studies of community development organizations of people with disabilities in Canada. Through interviews conducted with representatives of the organizations, content analysis of the organizations' websites and key documents, and a review of the relevant literature, this thesis will illustrate the complexities and currents in the use of ICTs by organizations of people with disabilities in Canada. The author concludes that ICTs have amazing potential for community engagement when used in conjunction with principles of the social model of disability. The author urges organizations of people with disabilities to embrace the use of ICTs as a method of community engagement and to harness their potential to further their goals.

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Dedication

This work is dedicated to my fiancée, Kristjan Joseph Delbaere. Thank you for making all my dreams come true.

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1 Introduction

Organizations of people with disabilities engage in many of the same activities and struggles as other community development organizations. Like other community organizations, they struggle with issues of time, resources and building the capacity of their members. With the advent of new technologies, or Information and Communication Technologies (ICTs) like computers and the Internet, organizations of people with disabilities embraced these technologies as having the potential to make their jobs easier. And while in some cases, the real potential of technology has exceeded their expectations, the use of technology has added new issues and concerns to the organizations' agendas.

Community development organizations of people with disabilities in Canada co-exist within the voluntary sector at varying levels of technological sophistication. While many organizations thrive in their uses of ICTs, expanding their membership, broadening the scope of their work and becoming more efficient in how they use technology to work within their organizations, many organizations are struggling with technology or refusing to adopt it as an organizational tool.

This project looks at the experiences with Information and Communication Technologies (ICTs) in three community development organizations of people with disabilities in Canada. Through a series of telephone interviews and through content analysis of documents and the organizations' websites, this thesis will highlight three examples of how organizations use technology in their own unique ways and how their level of technological sophistication has efforts at community development and engagement.

1.1 Background to the Research

Throughout the 1960s and 1970s, organizations of people with disabilities began to take root in Canadian society in the attempt to reverse the negative opinions that society had about the potential of people with disabilities. In the latter part of the 20th century, much of Canadian society has come to understand that people with disabilities are limited as much by environmental, attitudinal and structural barriers as they are by their impairments, and that with the right support, people with disabilities can participate as full and equal members of both society and the economy. Often referred to as the *social model* of disability, this conceptual model places the 'problem' of disability not within the individual, but within a society with inaccessible social, physical and political environments.[1] The outcome of a shift to a social model is an understanding that if the 'problem' is with society, and not the individual, then it is society that needs to change. Because the social model focuses upon political structures and other agents of structural oppression the natural outcome of a shift to a social model of disability is the increased politicization of the goals of the disability rights movement.

The Canadian disability rights movement is not unique in this respect. Across the globe, people with disabilities are responding to the social and economic barriers constructed by an ableist society. Michael Oliver (1996) argues that the disability rights movement in the UK has been "culturally innovative in that they are part of the underlying struggles for genuine participatory democracy, social equality and justice,

[1] Oliver, M. and C. Barnes. 1996. "Discrimination, Disability, and Welfare: From Needs to Rights," in J. Swain, V. Finkelstein, et al. eds. *Disabling Barriers-Enabling* Environments. (London: Sage)

which have arisen out of the crisis in industrial culture."[2] The crisis of which Oliver writes poses a direct threat to the community development goals of the organizations that comprise the disability rights movement. For this crisis is the tension between the goals of community development and the very logic of capitalism, which is challenged by the politics of difference and identity perpetuated by equality seeking groups, like organizations of people with disabilities.

This research seeks to understand the dynamics of community development in the emerging knowledge-based economy and its potential to engage people with disabilities through the use of Information and Communication Technologies (ICTs). Since community development organizations of people with disabilities are becoming more political in nature as a result of their understanding of and engagement with the social model of disability, any attempts at community development need to have political, economic and social foundations. Thus, these organizations will be highly affected by what many theorists are terming the onset of the 'knowledge-based' or 'new economy'.

Many analysts believe that the world economy has been undergoing a gradual restructuring process since the early 1970s.[3] This process is understood as a shift to a post-industrial form of economic development, increasingly based upon knowledge where human capital, skills, innovation and technology are necessary to be competitive. In the 'new economy', there is an ever-increasing demand for a well-educated and skilled work force in all parts of the economy.

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[2] ibid, p.285

[3] Dodge, M. and R. Kitchin. 2001. *Mapping Cyberspace.* (London: Routledge); Huws, U. 2003. *The Making of a Cybertariat: Virtual Work in a Real World.* (New York: Monthly Review Press); Garsten, C. and H Wulff. 2003. *New Technologies at Work: People, Screens and Virtuality.* (Oxford: Berg), Beckstead, D. and T. Vinodrai. 2003. "Dimensions of Occupational Changes in Canada's Knowledge Economy, 1971-1996," *The Canadian Economy in Transition Series*, No.4. (Ottawa: Industry Canada)

The onset of the knowledge-based economy has been much contested in the economic and political economy literature. Beckstead and Vinodrai (2003) claim that while many discussions about the new economy seem to pinpoint its onset in the 1990s, they argue that the 'new economy' has been in evidence in management and professional fields since the early 1970s. Statistics Canada identifies the 1990s as the time when Canadians began to have broad access to personal computers, the Internet and other forms of ICTs.[4] Dodge and Kitchin (2001) pinpoint the emergence of the Internet as we know it, with search tools, and the various modes of online communication such as Internet Relay Chat (IRC) as appearing in the early 1990s.[5] In order to understand how the knowledge-economy has affected the work of community development organizations of people with disabilities, this thesis will focus on the mid 1990s when most of these organizations probably came on board with the use of ICTs.

1.2 Definition of the Problem

Castells sees the emergence of information and communications technologies as central to the economic restructuring process, forming the basis for a new type of "socio-technical" organization.[6] The term 'socio-technical' can be used to represent the social meaning of human technological activity.

Writing his theory of historical materialism, Karl Marx extrapolated that the ways in which humans relate to the physical world and the way people relate to each other

[4] The Daily. 2002. "Information and Communications Technologies (ICT)," (Ottawa: Statistics Canada) available online: http://www.statcan.ca/english/freepub/13-605-XIE/2003001/classification/ict/2002note.htm

[5] Dodge and Kitchin, 2001, p. 11

[6] Castells, M. 1988. *The Information City: Information Technology, Economic Restructuring, and the Urban-Regional Process.* (Oxford: Blackwell)

socially are bound up together in specific and necessary ways.[7] While previous modes of economic development, such as feudalism or early forms of capitalism, were viewed by most economists as devoid of the social contexts in which development took place, the knowledge-based economy cannot be seen as devoid of social context. This view of economic development is what MacDonald calls a 'strategy of transformation', which draws out the broader social context in which economic development takes place.[8] As Dodge and Kitchin explain, the technologies that drive the knowledge-based economy are "grounded in social, political and institutional geographies and discourses that need to be carefully deconstructed."[9]

Part of the deconstruction process is an understanding of the ways in which ICTs are transformative technologies that change society and the central forms of social organization. In particular, ICTs disrupt a number of processes and foundational assumptions that form the basis of modernist society and epistemologies. Modernist systems are founded upon essentialist, dualistic categories, many of which ICTs and such related concepts as 'cyberspace', have begun to challenge. This thesis research will examine the relationship and relative importance of these constructs in the knowledge-based economy. For example, binary concepts such space/spacelessness, place/placenesses, public/private, fixed/fluid, and others, will be discussed within the literature review portion of this proposal. I will also be exploring these theoretical assumptions within the analysis of the research data.

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[7] Marx, K. and F. Engels. 1848. *The Communist Manifesto*. (Berlin: The Communist League)
[8] MacDonald, L. 2003. "Gender and Canadian Trade Policy: Women's Strategies for Access and Transformation," in C. Sjolander, H.A. Smith and D. Stienstra. Eds. *Feminist Perspectives on Canadian Foreign Policy*. (Don Mills: Oxford University Press)
[9] Dodge and Kitchin 2001, p. 6

With an understanding of the dynamics of our shifting economic organization comes a realization that all members of society may not be benefiting from this process. In fact, the Office for Disability Issues of the Canadian government argues that Canadians with disabilities are falling behind in the new economy. They write, "Not all Canadians are sharing equally in our country's strong economy and enviable quality of life....Those who live on the margins of society are often unable to get the education and skills they need, to gain meaningful and well-paid employment..."[10] The community development organizations studied in this project have been working toward changing the way that the new economy affects groups of people with disabilities in their communities. These organizations are those with a mandate to develop and provide for the social and economic needs of various people with disabilities, forming a distinct group on the basis of their shared interests rather than on location or geographic space. These groups are characterized by personal intimacy, moral commitment and social cohesion. The research will examine how the shift toward a knowledge-based economy has affected the work of community development organizations of people with disabilities in Canada. This will be a first step toward understanding the changing dynamic of community development that has occurred in concert to changes in society and the economy.

1.3 Objectives of the Research

The overarching objective of the research was to gather informative data on the perceived changes in the operation, effectiveness, and position of community development organizations of people with disabilities in Canada since the onset of the

[10] Human Resources and Social Development Canada. 2001. *The Strategic Plan of the Office for Disability Issues, 2002-2007*. (Ottawa: Government of Canada), p. 2

knowledge-based economy. Other objectives were to influence the activities and daily operation of community development organizations of people with disabilities to use ICTs more effectively, to inform policy-makers about the potential impact that funding of ICT development within these organizations could bring, and to share the data gathered with other researchers investigating the impact of ICTs in order to inform them of the issues specific to people with disabilities and their organizations.

1.4 Justification for the Research

ICTs like computers and the Internet promise to be as successful a medium of organization for people with disabilities as they are for other communities. Jamie Metzl describes the use of ICTs by non-governmental organizations in the human rights movement,[11] Nimijean and Rankin explore the use of online activism by the Canadian women's movement, Pendergrass, Nosek and Holcomb evaluate the design and use of a website for women with disabilities, and Bowker and Tuffin discuss the issue of online identity for people with disabilities. Since at least two of these references involve people with disabilities in their studies it is apparent that other scholars have identified the potential use of ICTs for the disability community. However, few researchers have studied the potential of these technologies for community development organizations of people with disabilities, whether they have had a positive or negative impact since the onset of the new economy, and how. These issues still need to be explored. The literature

[11] Metzl, J.F. 1996. "Information Technology and Human Rights," *Human Rights Quarterly*, 18, 4, p. 705-46; Nimijean, R. and P. Rankin. 2002. "Fighting for Change (and Survival?): Canadian Women's Movements and On- Line Activism." Paper presented to the annual meetings of the American Political Science Association, Boston, Mass., August 29 – September 1, 2002; Pendergrass, S. Nosek, M.A., Holcomb, J.D. (2001) Design and evaluation of an internet site to educate women with disabilities on reproductive health care. Sexuality and Disability, 19 (1) 71-83; Bowker, N. and K. Tuffin. 2002. "Disability Discourses for Online Identities," *Disability & Society*, 17, 3, p. 327-344

review section of the study will uncover what other research is being done and what gaps still exist.

The onset of the new economy and the growing importance of ICTs have a direct impact on everyone in Canadian society. The rapid expansion in investment in ICTs and the exponential growth of users in recent years is impressive. The World Wide Web is a rapidly growing information space, encompassing over 1 billion publicly accessible pages as of January 2000 and is likely to have grown significantly by 2005.[12] In North American alone, the total population of Internet users was 182.67 million in 2002, a high proportion of the 605.6 million people estimated online worldwide.[13] According to RHK, a US based global telecommunications consulting firm, the North American DSL market earned a significant $778 million in 2000.[14] These numbers indicate that the Internet is an important facet of investment growth in our economy. In fact, the most recent data that Statistics Canada has released on the IT industry suggests that it is a significant part of the Canadian economy. In 2003, the information technology sector accounted for $58.7 billion of Canada's GDP, 7% of the business sector GDP.[15]

As such a key part of the Canadian economy, community development organizations working toward the social and economic inclusion of people with disabilities need to devote significant time, attention, and resources to training, maintenance, and upkeep of this technology. A study conducted by the research firm Leverus says that more than 60% of website planning and organization by non-

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[12] Ibid, p. 3; DSL stands for digital subscriber line; it refers to the type of broadband connection that brings information to homes and businesses over ordinary copper telephone lines

[13] Nua, 2002, http://www.nua.ie/surveys/how_many_online/index.html

[14] http://www.pcb007.com/INTELLIGENCE/article.asp?id=566&display=2&langue=1 or http://www.rhk.com/index.jsp

[15] Vaillancourt, C. 2003. "Employment in the Computer and Telecommunications Industries," *Innovation Analysis Bulletin*, 5, 2

governmental organizations in Canada is conducted in-house.[16] Of the organizations surveyed by Leverus, at least 20% were spending more than 30 hours per week updating and maintaining their websites and upwards of $10,000 a year. With a significant amount of time and resources spent on web management and design, 50% of organizations reported being unsatisfied with their current design.[17] Clearly this has become an important tool to organizations but is creating a burden upon their already limited resources. If people with disabilities are to take part in the burgeoning knowledge economy, we need to better understand the issues, needs and concerns that influence people with disabilities, their partners and their advocates in community organizations.

1.5 Delimitations of Scope and Key Assumptions

This research is in no way intending to represent the situation of all organizations of people with disabilities in Canada. It is simply intended to illustrate three examples of how organizations of people with disabilities are fairing in the knowledge-based economy. The case studies represented in this thesis have come up with innovative uses for technology, creative ways to fund the technology-related expenses of their organization, and unique partnerships in order to make technology work for them and for the communities they serve. Further research would be required, including extensive quantitative data collection, in order to assess whether the experiences of these organizations accurately represent the situation of all organizations of people with disabilities across Canada or to make a comparison with organizations not representing people with disabilities.

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[16] Leverus. 2004. *Leverus Annual Internet Survey for Associations and Not-for-Profit Organizations, 2004.* (www.leverus.com)
[17] ibid

One assumption made during the formative stages of the research was that while technology can be a useful tool for organizations, there are both positive and negative effects of their use both on the organizations and on the people the organizations serve. It is assumed that organizations are spending a great deal of time, money and other resources on the creation, upkeep, and maintenance of technology and technology-related activities. It is also assumed that the technology-related needs of community development organizations of people with disabilities in Canada are largely unsupported by government.

2 Literature Review

2.1 Disability Studies

Disability Studies is an emerging multi-disciplinary field that arose in the last twenty years to form a critique of the inaccurate conceptualizations of disability in various fields of academic inquiry.[18] In her book entitled, *Claiming Disability: Knowledge and Identity*, Simi Linton examines Disability Studies as a field of inquiry, from its earliest history to its present configuration. According to her, "Disability Studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations."[19] The problems associated with previous fields of inquiry about disability revolved around a focus on how people with disabilities differed from 'the norm' rather than asking why we as a society understand those differences the way we do. Disability Studies is a striking field of studies because people with

[18] Linton, S. 1998. *Claiming Disability*. (New York: New York University Press)
[19] Ibid, p. 2

disabilities themselves have begun to reframe the questions being asked, whereas they have been under-represented in other fields of study.

2.1.1 Conceptual Models

One of the things that social science scholars do best is try to understand and illustrate, using concepts and symbols, various social phenomena. Models are, in essence, a likeness of reality, consisting of various symbols and concepts that represent the characteristics of the phenomenon that we are attempting to understand. Disability Studies scholars have created several conceptual models that are used to understand disability.

The *charity model* (also known as the pity or philanthropic model) presents an interpretation of reality in which disability is viewed as "the consequence of some tragedy, requiring a human response- most commonly of sympathy and charity."[20] The origins of this model can be traced back to times when people believed that disability could be attributed to bad luck or punishment for a wrongdoing. As scientific reasoning progressed, thinking around disability shifted toward one that embraced the *medical model* of disability.

The medical model portrays disability as equivalent to illness or impairment, the proper response to which would be professional intervention (usually from a rehabilitation therapist, physician or psychologist) to treat or cure the 'problem'.[21] The medical model places the 'problem' of disability within the individual, as something to be

[20] Enns, H. and A. Neufeldt. 2003. *In Pursuit of Equal Participation: Canada and Disability at Home and Abroad.* (Concord: Captus Press), p. 4
[21] ibid

fixed. This is often referred to as the *medicalization* or *professionalization* of disability.[22] When support is provided for people with disabilities, benefits are often provided in the form of social welfare programs and benefits are obtained through the approval of professionals in the medical, psychiatric and rehabilitation fields, who certify that their claims warrant support.[23]

The social model corrects many of the problems associated with the previous models from a disability rights perspective. It places the onus for the 'problem' of disability on societies that are built in ways that make the physical, social, economic and political structures inaccessible to people with a variety of impairments. The outcome of a shift toward the acceptance of a social model of disability is, therefore, that the "problems" associated with disability are placed within society, and it is society that must be changed. In this way, an understanding of society based upon a social model of disability leads the disability community into increased political action and social change. The unit of analysis is no longer an individual with impairment; it becomes a social and political system in need of change. For example, previous attempts to study the employment situation of people with disabilities often focused on the limitations imposed upon people due to their impairment. This often led to the conclusion that people with disabilities could not be employed.[24] However, the social model of disability illustrates

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[22] Michael Oliver prefers to call this model the individual model of disability rather than the medical model. He refers to the medicalization of disability as a component of the individual model. Oliver, M. 1990. "Individual and Social Models of Disability," paper presented at the Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospitals.

[23] Cameron, D. and F. Valentine. 2001. "Comparing Policy-Making in Federal Systems: The Case of Disability Policy and Programs- An Introduction," in D. Cameron and F. Valentine. 2001. *Disability and Federalism: Comparing Different Approaches to Full Participation.* (Montreal & Kingston: McGill-Queen's University Press)

[24] Baldwin, M.L. 1997. "Can the ADA Achieve Its Employment Goals?" *Annals of the American Academy of Political and Social Science*, 549, January, p. 37-54

that by changing the workplace, the nature of the work being done and by providing proper supports, people with disabilities can be productive members of the workforce. It is for this reason that the social model is so appealing to the disability rights movement. By politicizing the category of disability, one brings it from the private domain of professional intervention and medicalization and into the public domain of civil and political rights.

The next section, called Defining Community, will be used throughout the Literature Review to illustrate how each discipline defines the term *community*. The varying definitions of the term within each of the fields of study help to illustrate different approaches to community development by defining the scope of development and some of the key development practices, such as capacity building or economic development.

2.1.2 Defining Community

As an academic discipline, Disability Studies is closely linked to the disability rights movement. Some would even say that academics doing research in this area are as much activists as academics.[25] As we move into what many have termed an 'information-based society' it makes sense that the nature of activism is changing. Rather than hitting the streets for sit-ins and protests, many academics are forging a form of activism that is taking place within the realm of information. Making information available, accessible and usable by people with disabilities is a large part of the goal of Disability Studies. It is the proclivity toward political action and social change within disability community, that

[25] For a discussion of this see: Goodley, D. and M. Moore. 2000. "Doing Disability Research: Activist Lives and the Academy," *Disability & Society*, 15, 6, p. 861-82; Germon, P. 1998. "Activists and Academics: Part of the Same or a World Apart," in T. Shakespeare. Ed. 1998. *The Disability Reader: Social Science Perspectives*. (London: Continuum)

has led many scholars in both disability studies and the social movement literature to include the disability rights movement among the 'new social movements'.[26] It is from within the social movement literature that I locate the conceptual definition of community employed by Disability Studies.

The conception of community held by many within Disability Studies arises from the new social movement literature, infused with postmodern politics and ideals of radical democracy. For example, community is often referred to in Disability Studies literature in terms of political consciousness and collective identity. The 'disability community' is not a homogeneous, geographic community rather it is comprised of a group of people who, due to an understanding of common elements of identity, come together for a common purpose (Linton, 1998). Although this group identity has not been comfortably embraced by all disabled people, the strength of the disability alliance has led to several civil and human rights victories, such as the inclusion of disability as a marker of identity protected under the Canadian Charter of Rights and Freedoms.[27] Within the disability community, the quest for equality rights, independence, and social change is what brings people together.

The type of community development pursued by the disability movement tends to revolve around ways to achieve these goals. In the Disability Studies literature, this is most often referred to as 'capacity building'. This project defines capacity building as increasing the ability and skills of individuals, groups, and organizations to plan,

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[26] See for example: Campbell, J. and M. Oliver. 1996. *Disability Politics: Understanding Our Past, Changing Our Future.* (London: Routledge); Oliver, M. 1990. *The Politics of Disablement.* (London: MacMillan Press); Oliver, M. and G. Zarb. 1997. "The Politics of Disability: A New Approach," in L. Barton and C. Barnes (eds). 1997. *Disability Studies: Past, Present and Future.* (Leeds: The Disability Press)

[27] For an interesting illustration of this see the website: www.**disabilityrights**museum.ca/exhibits_v.php

undertake, and manage initiatives. The approach also enhances the capacity of the individuals, groups, and organizations to deal with future issues or problems. In 2003, disability organizations across Canada came together to form an initiative funded by the government of Canada's Voluntary Sector Initiative (VSI), called *Connecting People to Policy: A National Initiative to Build the Capacity of the Disability Community to Participate in and Contribute to the Policy Process*. The lead organizations for this project were the Council of Canadians with Disabilities (CCD) and the Canadian Association for Community Living (CACL). The initiative's goal was to "build the capacity of the disability community to engage with federal and provincial/territorial governments in policy discussion and development related to disability supports." The initiative also sought to "strengthen capacity of the community and governments to more effectively draw on the knowledge base of the disability community about disability support needs, issues, best practice and policy options." In March 2004, the initiative held meetings in Ottawa during which the participants identified three areas for policy development that would help equalize opportunities for people with disabilities in the social, political and economic realms: Employment, Income and Disability Supports.[28] The focus of most political activity is then to transform the social and economic realms in order to make them more receptive to the idea that people with disabilities can be equal and contributing members of those realms. Therefore, much of the community development in the disability community takes the form of consciousness-raising at the social level, lobbying for legislative change at the political level, and the creation of

[28] All information taken from: www.disability-supports-policy.ca accessed last July 19, 2004. The *Connecting People to Policy's* site is no longer accessible. The author participated in this series of discussions as a participant observer as part of a research study that took over the initiative's website once funding neared completion. See www.disabilitypolicy.ca to view the updated project website.

employment for people with disabilities in the economic realm, both by educating employers about the necessity of accommodating disabled workers, but also through training, skill and self-confidence building among people with disabilities themselves.

It is partly for this reason that researchers have begun to embrace a newer approach to research called Participatory Action Research (PAR). Stringer (1999) defines PAR as "disciplined inquiry (research) which seeks focused efforts to improve the quality of people's organizational, community and family lives."[29] PAR seeks to conduct research that engages people who have traditionally been called *subjects* as active participants in the research process and aims for practical outcomes related to the lives or work of the participants.[30] Many Disability Studies scholars have embraced PAR, which necessitates the direct involvement of people with disabilities in all aspects of the research process.[31] For this reason, many of the organizations that make up the disability community have become partners with academics involved in Disability Studies, using a PAR approach to research.

2.2 Community Development

Community Development (CD), also referred to in the literature as Community Economic Development (CED) is a subfield of Politics, Economics, Sociology and International Development Studies.[32] CD is defined as "action by people locally to create

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[29] Stringer, E.T. 1999. *Action Research*. 2nd Edition. (London: Sage Publications), p. 9

[30] ibid

[31] Doe, T. and Whyte J. 1995. *Participatory action research*. Paper presented at National Institute of Disability and Rehabilitation Research Conference on PAR, Washington, DC.; Litvak, S., L. Frieden, T. Doe and C. Dresden. 1995. "Empowerment, independent living research and participatory action research," Paper presented at the National Institute of Disability and Rehabilitation Research Conference on Participatory Action Research, Washington, D.C.; Whyte, W. Ed. 1991. *Participatory Action Research*. (Newbury Park: Sage Publications)

[32] The terms Community Development and Community Economic Development will be used somewhat synonymously throughout this thesis, even though it is acknowledge that they are not quite the same thing.

economic opportunities and enhance social conditions in their communities on an inclusive and sustainable basis, particularly with those who are most disadvantaged."[33] CD organizations create enterprises collectively owned and controlled by communities. The goal is to generate both social and economic benefits, bringing entrepreneurship and social strategies together to reduce poverty and disadvantage. CD tries to develop a more holistic approach to economic development at the local level, by linking economic development with a wider social and economic process.[34] It fits with the Participatory Action philosophies of Disability Studies because of its focus upon empowerment. CD organizations do not simply go into communities, set up enterprises and tell the people within the communities what they need to do to change their lives. Instead, CD views economic development as a process of *empowerment*, which Shragge defines as a "process that occurs both at a personal and political level...[and] involves changing power relations between individuals and groups and social institutions....[It is] a process of personal change as individuals take action on their own behalf and then redefine their understanding of the world in which they live."[35]

Like their counterparts in Disability Studies, CED practitioners have formed conceptual models to address what they see as inadequate methods of service delivery that are based upon charity and dependency. As Downing writes,

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CD takes a wider view of community development, as a whole, that encompasses many forms of development and does not have as strong a focus on economic development as CED, which can be considered a subfield of CD. Much of the CED literature, while relevant to CD refers to CED and that is why they are both being used.

[33] Downing, R. 2004. "The Role of the Social Economy in Strengthening New Media Development in Canada," (The Canadian Community Economic Development Network) available online: http://www.ccednet-rcdec.ca/en/docs/pubs/FINAL_RoleofSocialEconomyinNewMedia.pdf

[34] Shragge, E. 1993. *Community Economic Development: In Search of Empowerment.* (Montreal: Black Rose Books)

[35] Ibid, p. ii

> Community economic development models have been increasingly seen as ways of addressing both social issues and economic needs by giving people the supports, tools and resources they can use to get out of poverty and become economically and socially self-sufficient.[36]

Just as the disability community has argued for a more holistic view of service-provision that accounts for social, economic and political factors, so has CD tried to address these issues in ways that are sustainable and respectful to the parties involved.

The links between CD and Disability Studies are clear. Many of the organizations of the disability community work in Community Development, whether they are non-profit organizations or registered cooperatives. Some may be advocacy organizations with a particular focus upon the economic and social empowerment of people with disabilities. These are the organizations that Disability Studies scholars are increasingly working with to learn more about the issues that concern people with disabilities. These organizations may also be doing a significant amount of research of their own. The Center for Community Development & Disability at Southern New Hampshire University in the US is a research-based centre that seeks to facilitate leveraging CD resources and expertise in the service of people with disabilities. While there are currently no Canadian centers that I am aware of, many CD departments and research organizations in Canada do have a disability stream in their work.[37]

CD and Disability Studies also have similar principles that guide their work. In his book, *The Community Economic Development Movement: Law, Business & Social Policy*, William H. Simon writes that CD is comprised of three core defining principles.[38]

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[36] Downing, 2004, p. 5

[37] For example, the Community Futures Development Corporations of Western Canada work with entrepreneurs with disabilities in a variety of programs and services. See their website: http://www.communityfutures.ca/provincial/

[38] Simon, W.H. 2001. *The Community Economic Development Movement: Law, Business & Social Policy.* (London: Duke University Press)

The first principle is that CD efforts focus upon the development of housing, jobs or business opportunities for low-income groups. People with disabilities are often considered a low-income group, as the majority of people with disabilities in Canada live in low-income situations. The organizations that comprise the disability community focus their efforts on many of the same activities. The second principle is that the lead role is to be played by non-profit NGOs (non-governmental organizations). The disability community holds similar principles. The third principle is that CD should be accountable to residentially defined communities. This principle is different for the disability community, as that community focuses on shared interest rather than spatial geography. With that said, the principle is the same in that any development efforts must be held accountable to the target community. Consumer-control is an important principle to the organizations that comprise the disability community (see section 4.3.1 Community Development below).

2.2.1 Defining Community

From a very practical standpoint, CD defines community as a geographically-based locale.[39] The reason for this understanding is rooted in CD's long-term goals, which are social and economic development. To understand community in geographically-specific terms makes it much easier to measure economic development. Indicators can be developed to measure economic development within a geographically-defined space.[40] It is much more difficult to amass data about the economic development of diffuse groups of people who might be dispersed across vast areas of geographic space, especially when that space spreads across jurisdictional, territorial and even

[39] Shragge, 1993
[40] ibid

national boundaries. That is not to say that there is not an interest-based aspect to CD, only that the common interests of the group are rooted in the geographic location of their communities. As Simon notes, "the geographic focus of CED strategies creates a focal point for collaborative effort and gives physical expression to a sense of common interest and identity."[41]

The understanding of community in CD is being affected by many outside factors. Globalization, economic restructuring and the impact of increased communications makes it harder to ignore the effects of outside forces. The Internet, and the use of websites in particular, has widened the scope of community in CD enormously.[42] While the discussion of this in the literature is still relatively nascent, it is safe to say that CD practitioners, scholars and researchers are considering the effects of online communities, vastly dispersed populations, and the impact of social identity upon the communities with which they work.

Based upon a review of the literature, I believe that CD as a field has not fully embraced the use of technology, particularly online forms of communication. I could be wrong in this presumption, but a scan of the literature did not turn up much information relating to online uses of technology. This may be explained by one of the defining principles of CD, that development efforts should replace remote impersonal relations by promoting face-to-face encounters.[43] Part of the idea of this principle is that one is likely to be more understanding of and respectful toward the interests of people of whom one is

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[41] Simon, 2001, p. 50
[42] Shearman, C. 1999. *Local Connections: Making the Net Work for Neighborhood Renewal.* (London: Communities On Line
[43] Simon, 2001

personally aware.[44] This concept is important to CD practitioners who are overcoming issues of distrust and conflict between absentee owners and their tenants of customers, and bureaucrats and the people affected by their policies and programs at the most local level. Because of the geographic focus of CD and the nature of work done, online encounters and development have been met with skepticism. That is not to say that it could not be useful, further work needs to be done by CD practitioners to see if there is a place for the use of Information and Communications Technology within CD.

2.3 Community Informatics

Perhaps the newest of the fields under consideration, Community Informatics is a growing field of inquiry that looks at the development of information systems for supporting community activities. As a field of inquiry, its roots can be traced to the community networking movement in the US and the Scandinavian telehouse experiments as described by Qvortrup (1987) and Cronberg et al (1991).[45] Community Informatics Theory is being used to describe the academic discipline and practice for systematically approaching Information Systems from a "community" perspective.[46] CI provides the technological linkage to bring together the two main fields of inquiry that this thesis will examine, Disability Studies and Community Development.

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[44] ibid

[45] Farrington, C. and E. Pine 1992. "Community Memory: A Case Study in Community Communication," in P. Agre and D. Schuler. Eds. *Reinventing Technology, Rediscovering Community: Critical Explorations of Computing as a Social Practice.* (Norwood: Ablex Publishing); Hauben, J.R. 1995. "A Brief History of Cleveland Free-Net," *The Amateur Computerist*, 7, 1, available online: http://www.prometheusonline.de/heureka/kommunikationswissenschaft/monografien/hauben/brief.htm Kubicek, H. and R. Wagner. 2002. "Community Networks in a Generational Perspective: The Change of an Electronic Medium Within Three Generations," *Information, Communication, &Society, 5, 3, p. 291-319;* Qvortrup, L. ed. 1987. *Social Experiments with IT and the Challenge of Innovation.* (New York: Kluwer Academic Publishers); Cronberg et al 1991.

[46] Gurstein, M. 1999. "Community Informatics," (St. Petersburg: Centre of Community Networking and Information Policy Studies) available online: http://www.communities.org.ru

In a literature review of CI initiatives, Keeble and Loader (2004) define CI as "initiatives designed to explore the potential transforming qualities of the new ICTs for community development, economic regeneration, democratic renewal, and social support."[47] CI works as a bridge to provide a multidisciplinary research platform to undertake rigorous and critical analysis which can develop our understanding and bridge the divide between policymakers and researchers. In trying to understand how the use of ICTs can help Community Development organizations working with people with disabilities make better use of these technologies for organizations' purposes, CI provides an interesting link between those two academic fields of inquiry.

CI can be a useful tool for researchers working with policymakers to address issues of concern to particular communities. In addressing the Digital Divide, governments' policy responses often focus upon the role of the voluntary sector to develop local projects designed to provide public access, training and support for the adoption of ICTs.[48] The aim of many CI initiatives has been to provide a community location for those unable to access the Internet. In Canada, the Community Access Program (CAP) of the federal government provides funding for community organizations to provide public access to technology in a variety of community locations (libraries, organizations' offices, etc). Aside from increased funding cuts to this program in recent years, the literature also suggests that initiatives such as these may act to disguise widening differential access and use of ICTs.[49] Programs such as these allow governments to assume that access to ICTs is equal for all social groups, without

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[47] Loader, B.D. and L. Keeble. 2004. *Challenging the Digital Divide? A Literature Review of Community Informatics Initiatives.* (York, North Yorkshire: The Joseph Rowntree Foundation), p. 4
[48] PAT 15. 2000. *Closing the Digital Divide: Information and Communication Technologies in Deprived Areas: A Report by Policy Action Team 15.* (London: DTI)
[49] Keeble and Loader, 2004

considering the impact of different types of access according to socio-economic origins. For example, there is an interesting discussion taking place in the literature surrounding the impact of the type of internet connection employed and the level of sophistication of Internet use.[50] Davison and Cotton (2003) argue that broadband users experience the Internet differently and that in determining who is likely to spend more time online, the type of connection is far more important than other digital divide demographics such as education, race or gender.[51] This argument does not, however, account for the effects of disability or inaccessible web design. In this sense, research from the field of Disability Studies could have a beneficial impact upon this dialogue.

One of the strengths of CI is that it attempts to avoid overly technical approaches which often approach ICTs as a determining force for change and which give little space for human choice in their analysis. CI places human agency as an essential component for "the creative adoption, alteration and diffusion of the new technologies" into community relations.[52] The literature refers to the 'social shaping of technology' which means that the technology is of secondary importance to the social, political, economic or cultural objectives of a project.[53] From this perspective, technology is not value neutral. The adoption of ICTs is heavily influenced by the "intentions of the designers, the perceptions and expectations of the users and the unintended uses which emerge over time."[54] Heavily influenced by the feminist critiques of science put forth by such writers as Sandra Harding (1986)[55], this understanding of technology can be used by technological

[50] Davison, E. and S.R. Cotton. 2003. "Connection Discrepancies: Unmasking Further Layers of the Digital Divide," *First Monday*, 8, 3, Available online: http://www.firstmonday.org/issues/issue8_3/Davison.html
[51] Keeble and Loader, 2004
[52] Ibid, p. 4
[53] ibid
[54] Ibid, p. 39
[55] Harding, S. 1986. *The Science Question in Feminism.* (Ithaca: Cornell University Press)

determinists to argue that there is an inherent bias in the very nature of the technology that makes it inappropriate for emancipatory social aims. It can also be used by this group's detractors, to argue that by being aware of the social implications of technology, its uses can be shaped to counter this bias. This discussion would highly benefit from the input of theorists and scholars from Disability Studies and will be discussed in more detailed in the section entitled Implications for Theory.

2.3.1 Definition of Community

The definition of community in CI is contested among academics.[56] Putnam (2000) and Delanty (2003) employ similar definitions of community as the one given by Keeble and Loader (2004), which describes community as "an 'intermediate space' between the individual/family and larger social structures, such as government."[57] Many academics still employ more traditional definitions of community based upon geographic space.[58] However, at a time when there is concern that such community relations and intermediate spaces are declining (see the discussion in the following section entitled 'Space/Spacelessness' below), the increasing use of ICTs in community networking and development are causing academics in CI to reconsider their understanding of community. The debates surrounding community and ICTs are now centering around whether or not ICTs are a contributing factor in the loss of community or a means of regenerating a loss of community by empowering communities to network with one

[56] Plant, R., H. Lesser and P. Taylor-Gooby. 1980. *Political Philosophy and Social Welfare.* (London: Routledge & Kegan Paul)
[57] Putnam, R. 2000. *Bowling Alone: The Collapse and Revival of American Community.* (New York: Simon & Schuster); Delanty, G. 2003. *Community.* (London: Routledge); Keeble and Loader, 2004
[58] Shearman, 1999

another.[59] Those authors writing from within a more traditional understanding of community based upon geographic space argue that online 'virtual communities' may further weaken local ties which bind communities together.[60] Conversely, those that employ a similar definition to the one quoted above (Keeble and Loader 2004) are enthusiastic about the capacity of ICTs to empower community networks.[61] Such ambiguity within the literature needs further clarification through more systematic research to inform a more comprehensive dialogue about how academics working in CI understand the concept of community.

2.4 Human Geography

Human Geography is an interesting field of study that provides a bridge between the study of the natural and social sciences. Study within this field tends to focus on two themes. The first studies the similarities and differences between places, localities and areas within a range of social, cultural, economic and political aspects of human life. The second studies the interactions between individuals and their environments.[62] Brendan Gleeson, writing on the topic of geographies of disability, insists that until recently, the impact of disability in social, economic, and political life has been neglected by human geographers.[63] Although this "disciplinary silence" has been somewhat remedied since

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[59] Keeble and Loader, 2004

[60] Kraut, R., M. Patterson, V. Lundmark, S. Kiesler, T. Mukopadhhyay and W. Scherlis. 1998. "Internet Paradox: A Social Technology that Reduces Social Involvement and Psychological Well Being?" *American Psychologist*, September, p. 1017-31

[61] Schuler, D. 1996. *The New Community Networks: Wired for Change.* (Reading: Addison-Wesley); Kavanaugh, A.L., A.M. Cohill and S. Patterson. 2000. *Use and Impact of Community Networking in Blacksburg.* (Blacksburg: Blacksburg Electronic Village Hall)

[62] Rubenstein, J. 1999. *The Cultural Landscape: An Introduction to Human Geography.* 6th. ed. (Upper Saddle River: Prentice-Hall)

[63] Gleeson, B. 1999. *Geographies of Disability.* (London: Routledge)

the 1970s, the body of literature and number of academics committed to the examination of the social needs of people with disabilities within geographic space remains small.[64]

Gleeson argues that human geography can play an important role in helping to equip people with disabilities with a "valuable conceptual, professional and practical resource" to use in their relations with service providers, professional and institutional agencies and the wider public.[65] As human geographers have realized that "space is a social artifact that is shaped by the interplay of structures, institutions and people in real historical settings," knowledge about how space is produced, and for whom, can help aid people with disabilities in their struggle for social, political and economic equality.[66] In this sense, the discussions surrounding space within the field of human geography sound much like arguments made within the field of Disability Studies for Universal Design Principles to be included in all planning of the built environment.

Even within human geography, the importance of disability as an aspect of identity, especially as it relates to group identity, cannot be denied. This interest in the spatial realities of disability has even spawned a subfield of Disability Studies that looks specifically at geographies of disability, with writers such as Rob Kitchin, Vera Chouinard, Deborah Metzl and Nancy Hansen taking up the "challenge… to pursue a geography with disabled people which seeks the goals of material justice and political emancipation that are shared by contemporary movements."[67] Gleeson urges that work within human geography needs to be more prescriptive than descriptive. It must

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[64] Ibid, p. 1
[65] Ibid, p. 2
[66] Ibid, p. 2
[67] Gleeson, B.J. 1996. "A geography for disabled people?" *Transactions of the Institute of British Geographers*, 21, p. 387-396

contribute in some broader way to the work of the disability rights movement.[68] Vera Chouinard writes that there is a need for new spatial research on disability that "not only unsettles ableist [i.e., oppressive] explanations of social processes and outcomes, but also considers how such knowledge can be used to further political struggles against environments that exclude and marginalize disabled people."[69]

Hansen has assessed the impact of technology on the experiences of people with disabilities and writes that software innovations have ensured that manual dexterity and physicality are no longer determinant of the ability of people with disabilities to work, communicate and function in an increasingly technological world.[70] However, she cautions that, "although technology can hold great potential for disabled people, technology is not social destiny, it works in conjunction with a multiplicity of other factors," such as the regular types of supports that people with disabilities need on a regular basis. An important part of supporting people with disabilities includes understanding the disabled person's organization of time and speed factors associated with their disability or impairment. Perhaps one of the greatest contributions that disability geographers like Hansen, Kitchin and Chouinard have made to the field of human geography includes the understanding that there is a "pressing need to acknowledge the embodied time and space needs of disabled employees in the quest for 'equality.'"[71]

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[68] Ibid
[69] Chouinard, V. 1997. "Making Space for Disabling Differences: Challenging Ableist Geographies," *Environment and Planning D: Society and Space*, 15, 4, p. 379-387
[70] Hansen, N. 2002. "On Approval: The Geography of Disabled Women and Work," Paper given at the *New Directions in Disability* seminar series, Centre for Disability Studies, University of Leeds, Leeds, April 10th, 2002
[71] Ibid, p. 6

2.4.1 Definition of Community

The definition of community traditionally held by human geographers understood community as a geographic space that bound people together because of their common interests in sharing that space. As Simon notes, the act of living together in a common area can "give physical expression to a sense of common interest and identity."[72] Many outside factors have had an influence upon the understanding of community held in human geography. Globalization, that often theorized and rarely defined phenomenon that is said to render geographic space insignificant, has had its impact upon human geography as well. It is understood that the economic effects of globalization have facilitated the outsourcing of jobs, the movement of plants and offices and the swift movement of goods and services due to the increased ease and effectiveness of the use of Information and Communications Technologies.[73] As communication and travel become easier and faster, it no longer matters where factories, offices, warehouses, or other sites of production are located. Globalization has been understood within human geography as something that tears communities apart.[74] However, as the understanding of community begins to change, so do theories around globalization.

Another body of literature having an effect upon the understanding of community in human geography is the literature on and by the new social movements.[75] Feminists, in particular, have theorized a notion of community that is not dependent upon geographic space, but is rather based shared interests and collective identities.[76] This notion of

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[72] Simon, 2001, p. 50
[73] Dodge and Kitchin, 2001
[74] ibid
[75] Cohen, R. and S.M. Rai. Eds. 2000. *Global Social Movements*. (London: Athlone Press)
[76] Dodge and Kitchin, 2001; Naples, N.A. and M. Desai. Eds. 2002. *Women's Activism and Globalization: Linking Local Struggles and Transnational Politics*. (New York: Routledge)

community makes geographic space less important, although not irrelevant, because geography is no longer what brings people together. This literature theorizes that people come together, despite geographic space, due to common interests and identities. It is shared notions of beliefs and an understanding of common life experiences that bring people together, often to work toward a particular goal.[77]

Together the impact of these two bodies of literature upon human geography has been to cause researchers in this field to reconsider the importance of geography to notions of community. While most human geographers still assert the primacy of geographic space in community, the discussion has widened to consider the impact of other notions of community upon people living in geographic space.

2.5 Common Themes in the Literature

There are many overlapping themes that appear throughout the literature discussing the social implications of the use of ICTs. Some of the most interesting discussion are advanced by researchers who appear in the literature of more than one field.

One writer found within both the Disability Studies and Human Geography literature is Robert Kitchin.[78] In *Mapping Cyberspace*, Dodge and Kitchin discuss the importance of Information and Communications Technologies as transformative agents in society. They argue that ICTs are "facilitating a process of restructuring, radically altering social, cultural, political, institutional and economic life."[79] The key to the transformative capacity of ICTs, they argue, lies within their ability to disrupt a number

[77] ibid
[78] You can find out more about his work by visiting his website, http://www.kitchin.org
[79] Ibid, p. 13

of processes and foundational assumptions associated with modernist society and founded on essentialist, dualistic categories. They outline binary constructs that ICTs influence, some of which are not necessarily principles of modernistic societies, but which highly influence our understanding of the social world. These constructs are dualistic categories that serve as a useful framework for understanding the multidisciplinary nature of the study of the social implications of ICTs.

2.5.1 Space/Spacelessness

The first construct that Dodge and Kitchin outline, 'space', is one of the core concepts used in many conceptual models of Human Geography. In modern society, it is recognized that social relations are formed by spatial concerns. The "modern logic of space" that Dodge and Kitchin refer to explains such phenomena as the location of cities to maximize capitalist production and consumption.[80] Many theorists now argue that ICTs have caused this process to rely less and less on spatial location. For example, it no longer matters where companies locate their head offices, as production locations can be anywhere around the world and still remain connected to head office by e-mail, fax, and telephone. Kitchin, in particular, argues that while capitalist relations may have, to some degree, found freedom from modernist spatial logic, social relations are still reliant on those spatial boundaries.[81] He argues that geography does still matter as an organizing principle and a constituent of social relations. The 'death of distance' can only occur if

[80] Ibid, p. 13
[81] ibid

everywhere offers equal opportunities for production and consumption and if the costs and accessibility factors surrounding the use of ICTs find resolve.[82]

2.5.2 Place/Placelessness

Space and place are highly related concepts. While space refers to the geographic location of human interaction and social, political and economic organization, place refers more to the process of communication and to a feeling of attachment and belonging to a particular place.[83] This is not a new concept. Political scientists and political philosophers have long extrapolated the importance of public (vs. private) place. For example, as far back as the writings of Aristotle, political thinkers associated the city with society or the community. In contrast to our understanding of government today, political in Greek political thought was not confined to the state, but was conducted in everyday life, through the self-government of citizens.[84] Open public places were hotbeds of political activity, full of great orators who shared their thoughts about how society should be governed. In fact, Aristotle's student Plato expressed his dismay with the loss of community that arose simply from the onset of the written word.[85]

Plato believed that the true self could not be expressed in or defined by written text.[86] One could say this was the first effect of modernity upon social and political life, or the first technological revolution. Plato believed that "[a] person must speak his or her mind directly to confront the problems of society and maintain one's personal ideals."[87]

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[82] Ibid; Morley, D. and Robins, K. 1995. *Spaces of Identity: Global Media, Electronic Landscapes and Cultural Boundaries*. (London: Routledge)
[83] Dodge and Kitchin 2001
[84] Delanty, 2003
[85] Wood, A.F. and M.J. Smith. 2001. *Online Communication: Linking Technology, Identity & Culture.* (Mahwah: Lawrence Erlbaum Associates, Publishers)
[86] ibid
[87] ibid, p. 6

In light of this statement, what would Plato think of our society today and the ideals of the individual who comprise it? Would he blame much of society's ills on the fact that communication has become increasingly mediated, not just through computer technology, but through other ICTs as well? It is these and other considerations of the effects of technology that Dodge and Kitchin explain as a loss of place. Society does not make the space for public conversation anymore and, therefore, alternative places have arisen online.

Placelessness is not a new concept, but a feature of modern society. Many argue that the sense of belonging and community that existed previously are being lost in modern society.[88] Therefore, it is within the discussion of place/placelessness in human geography that an interesting dialogue regarding the definition of community can be located. Many scholars have long believed that modernity has taken politics out of the social and confined the political to the state.[89] Community is thus seen as something that was lost with modernity, and that needs to be recovered. But does community necessitate an attachment to geographic space? Relph (1976), one of the first geographers to examine the notion of 'authentic' place, argues that inauthentic places are caused by a weakening of the identity of places to the point where they not only look alike, but offer the same possibilities for experience.[90] The process of creating inauthentic places is hastened by globalization to the point where inauthentic places are the prevalent mode of industrialized mass societies.[91]

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[88] Relph, E. 1976. *Place and Placelessness*. (London: Pion)
[89] Delanty, 2003
[90] Relph, 1976
[91] ibid

The question then becomes, how important is place to one's identity and is that place reliant upon geographic location, or simply a feeling of belonging and attachment? To what extent is cyberspace fostering the provision of alternative, authentic places for online interaction based around a notion of community built upon shared interests and common goals rather than geographic location? These questions have opened a dialogue within the field of human geography as to the potential for alternative views of community, such as those previously postulated by political studies and sociology. Rheingold (1993) is interested in how cyberspace can provide and antidote to placelessness by providing alternative and more authentic places.[92] According to Jess and Massey (1995), this is very possible.[93] They argue that based upon the new modes of interaction provided by online environments, new forms of social relationships are developing that are centred upon common interests and affinity rather than coincidence of location.[94] Dodge and Kitchin explain that

> This means that individualistic, like-minded people join forces to form public-based communities; cyperspace offers the opportunity to reclaim public space and recreated online the essence and nature of authentic places which are disappearing in geographic space.[95]

However, while Dodge and Kitchin see the potential of online communities and authentic places, they caution that society needs to be careful that the creation of online community does not replace more traditional notions of community rooted in geographic spaces. Kitchin in particular, with his connections to Disability Studies, understands that there must remain a balance of authentic places both online and in geographically based

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[92] Rheingold, H. 1993. *The Virtual Community: Homesteading on the Electronic Frontier*. (New York: Addison-Wesley)
[93] Jess, P. and D. Massey. 1995. "The Conceptualisation of Place," in Massey and Jess. Eds. *A Place in this World? Places, Cultures, and Globalization*. (Oxford: Oxford University Press)
[94] ibid
[95] Dodge and Kitchin 2001, p. 17

communities. Many without access to the technology and resources to be online risk being cut off completely from any sense of community if we move all places online. The creation of authentic places online must be viewed simply as a complement to more traditional notions of community.

2.5.3 Industrial/Post-Industrial

As we move into what many have called a "Knowledge-Based Society" we move into mode of economic organization in which information and knowledge replace labor and capital as the central variables of the Western economy.[96] Dodge and Kitchin point out that "one of the characteristics of the modernization of society was the division between home (private) and other spatial arenas (public) that accompanied the separation of places of work from places of living."[97] The significance of this shift to the discussion at hand, is that many theorists in many fields across the social sciences have documented what they consider to be a loss of public spaces. This relates back to both the discussion of place and space in the preceding sections. Instead of street-front stores and cafes where people can gather to discuss current events and open new forms of dialogue, industrialization has brought us large, impersonal shopping malls and cookie-cutter coffee shops like Starbucks. The importance of these public spaces of discussion are lost and people resort to online environments rather than public spaces. The danger is akin to that mentioned in the previous section, for those groups that cannot for whatever reason join these communities are being cut off from the new social dialogue and many important voices are being lost.

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[96] Poster, M. 1995. *The Second Media Age.* (Oxford: Polity)
[97] Dodge and Kitchin 2001, p. 18

2.5.4 Broadcasters/Listeners

While not a particular aspect of modernity, Dodge and Kitchin also explore the importance of various modes of communication because the use of ICTs has begun to challenge modernist structures of society.[98] In particular, the forms of mass communication used in modernist societies have been altered to the point that many traditional consumers are becoming producers, each with their own website, message board, and captive audience. ICTs are also changing the ways in which we produce and exchange knowledge. Of particular relevance to this thesis are the various forms of *computer-mediated communication* (CMC) that have altered the way that both users and producers of information operate in the global economy. CMC differs from both verbal communication and immediate communication. Verbal communication, words spoken between two individuals or a group of individuals, and immediate communication, a process where messages are transmitted more or less directly, have been traditionally favored modes of communication.

E-mail is one of the most popular and familiar modes of computer mediated communication. E-mail involves the exchange of textual messages between two or more parties. It arrives quickly, is easy to use, and is probably one of the most accessible forms of CMC to the most people, in that it is available free through services like Hotmail and Yahoo and is compatible with most types of screen-reading software.

Bulletin Board Systems (BBS), newsgroups and listserves all fall under the same category of CMCs. Also a form of text-based communication, they differ from e-mail in the size of audience that can be reached. Individual computers send messages to a single

[98] ibid

computer address. The program then posts these messages to a main site that visitors can access and read at their discretion. In the case of listserves, these messages are forwarded to recipients on a central e-mail list, usually on a daily basis.

2.5.5 Real/Virtual

Dodge and Kitchin write that "many analysts believe that cyberspace significantly destabilizes a foundation assumption of modernist epistemologies, the separation of real from virtual, genuine from fake."[99] This set of constructs outlined by Dodge and Kitchin add to the many philosophical discussions taking place across most academic disciplines regarding postmodernist interpretations and understandings of the world. The 'postmodernist' or 'poststructuralist' perspectives hold that the historical roots of current utopian views about the potential of new technologies are found in the 19th century ideals of social progress, determinism and positivist epistemology.[100] The modernist drive at continual development, whether in science or technology, is the root of the shift toward a knowledge-based economy that relies upon the latest technological fix for whatever social problems occur either because of this shift or as an unforeseen result of some form of technological development.

French social theorist Jean Baudrillard (1983) argues that in postmodern society, most of the places we understand in our world are simply 'hyperreal' copies of the original.[101] In the 'New Economy', the increasing commodification of society means that people now consume places as well as goods and services.[102] As particular spaces gain

[99] Ibid, p. 21
[100] Pitkin, 2001
[101] Baudrillard, J. 1983. *Simulcra and Simulations*. (New York: Semiotext(e))
[102] ibid

popularity, they are increasingly reproduced in places outside of their original contexts. For example, as the local British pub becomes trendy, they can be found on streetcorners in Winnipeg, New York or New Hampshire. While they may look like an authentic British pub, they are merely copies of the original. According to Baudrillard, this form of hyperreality undermines our ability to tell genuine from fake. Relph's (1976) discussion of 'authentic' vs. 'inauthentic' places (see Place/Placelessness above) could benefit from Baudrillard's discussion of hyperreality. Perhaps Relph would find that these 'hyperreal' locations are expressions of inauthentic places. Virtual communities, which Relph argues can create authentic spaces online, are examples of hyperreality.[103] Therefore, further research and theorizing is needed to better understand whether or not online communities can overcome spatial boundaries to create authentic places in which people with disabilities can organize.

2.5.6 Nature/Technology

In modernist systems of thought, the natural is considered distinct and separate from the technological. ICTs disrupt the nature/technology distinction by aiding the reconfiguration of the boundaries between people, their bodies and the world around them. This distinction has particular significance for people with disabilities for whom identity is highly connected to the body. In our technological society today, we have increased our forms of mediated communication to the point that some people in society can have fully interactive lives without setting foot outside their homes. This has significant implications for the body and the importance of our bodies for our daily existence.

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[103] Relph, 1976

People with disabilities experience life through their bodies, as do we all. However, people with disabilities often describe the advantages of not identifying the self with the body. According to Susan Wendell,

> People with disabilities often express a strong desire not to be identified with their bodily weaknesses, inabilities, or illnesses....When the world sees a whole person as disabled, the person's abilities are overlooked or discounted....It is good psychological strategy to base our sense of ourselves, and therefore our self-esteem, on our intellectual and/or emotional experiences, activities and connections to others.[104]

The Internet, and the various forms of CMC that occur in that environment, can be a positive way for people with disabilities to overcome the physical limitations of their bodies and to engage with the world in a different way. In this space, people with disabilities are relatively safe to explore their "intellectual and/or emotional experience activities and connections to others" as referred to by Wendell, in an environment where the body is not present and is, therefore, not an issue.[105]

These discussions, arising out of Human Geography and Disability Studies, have benefited from, critiqued and expanded upon feminist discussions of the body. For example, Donna Haraway is a feminist scholar who wrote a book called *Simians, Cyborgs and Women*, that examines how technology influences our identity and our bodies.[106] This book critically examines the essentialist distinction between nature and culture. Haraway argues that if knowledge is constructed than nature is culturally produced.[107] She looks at how the dominant patriarchal systems can be challenged to

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[104] Wendell, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability.* (New York: Routledge), p. 176
[105] ibid, p. 176
[106] Haraway, D. 1991. *Simians, Cyborgs and Women.* (London: Free Association Press)
[107] ibid

rebalance the position of women in society. She hypothesizes that cyperspace has the potential to free women of gender relations and sexual hierarchy because of "the physical differences that underpin social relations in geographic space will be eliminated, or at least radically subverted, within a space where the natural and technological are one."[108] Disability Studies scholars have critiqued not only Haraway's work, but poststructuralist analyses of the body in general.[109] Erevelles argues that the material reality of people with disabilities, the struggles against social oppression, poverty and segregational practices, should not be simply cast aside and forgotten when constituting the disabled subject as 'cyborg'.[110] Moreover, postructuralists like Haraway and Butler see the body as wholly constituted in language, which Erevelles contests and deconstructs using historical materialism to argue that disability is a historical construct within the broader context of the global political economy. While Haraway argues that nature is culturally produced through language, Erevelles illustrates that the material realities of people with disabilities in relation to the social division of labour are much more relevant to the specific historical contexts of people with disabilities.[111]

2.5.7 Fixed/Fluid

The final binary construct considered by Dodge and Kitchin (2004) also relates to identity. A modernist conception of identity is essentialist in its formulation- rational, stable, centred and autonomous. Online communities demonstrate that identity can be unstable, diffuse, fluid and manipulable. The relative autonomy that online communities

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[108] Dodge and Kitchin, 2004, p23
[109] Erevelles, N. 2001. "In Search of the Disabled Subject," in J. Wilson and C. Lewiecki-Wilson. Eds. 2001. *Embodied Rhetorics: Disability in Language and Culture.* (Carbondale: Illinois Press), p. 92-111
[110] ibid
[111] ibid

afford, and the disembodied nature of online activity make it rather easy for people with disabilities to construct their own identity online. This creates a situation that strongly disrupts modernist understandings of identity.

The self, in online environments, can be thought of as a discourse in which identity is considered through multiple experiences. The literature on online identity creation is actually quite extensive. However, it lacks an analysis of the implications of the use of ICTs for the identities of people with disabilities. In the literature on online identity construction and people with disabilities that does exist, three key issues arise: how and why to disclose disability, general understanding about the social implications of the use of ICTs, and the conceptual frameworks which inspire and guide our use of these technologies. Further research taking a multidisciplinary approach would add significantly to this body of literature.

To determine the negative, as well as the positive, impacts of the shift to a knowledge-based economy on community development organizations of people with disabilities, many of the theoretical implications are unintentional. Just as with technological progress, we don't often know what the impact of our work will be.

3 Methodology

3.1 Research Questions

The research had four main research questions:

1. How has the onset of the knowledge-based economy affected community development organizations of people with disabilities?

2. Have these organizations noticed changes in how they structure their work because of the importance of ICTs (be it in resource allocation, staffing, communications, etc) in the knowledge-based economy?

3. Have organizations noticed a shift in their roles in the voluntary sector from the onset of the knowledge-based economy and a shift toward the importance of ICTs?

4. Since Community Development tends to understand community in a geographic sense (see Defining Community subsection of Community Development section of Literature review) is technology a way to overcome the limitations that such an understanding of community presents for people with disabilities for whom geography acts as a barrier (for example, those with a lack of mobility)?

3.2 Research Design

The project consists of three qualitative case studies of community development organizations of people with disabilities who have had differing experiences with technology. The case studies will consist of organizations who: have made significant attempts to harness the tools of ICTs for community development purposes, those whose attempts have been more modest, and those for whom technology has posed a barrier.

3.3 Case Study Selection

The following organizations have been chosen with the advice of leaders in the disability community, information gathered on the Internet, and initial conversations with leaders of the organizations to determine their organization's suitability for the study. An attempt was been made to have one organization from the western region of Canada, one from Central Canada, and one from the Eastern region of Canada, however, the

organization chosen from Western Canada declined to participate and another organization from Central Canada was chosen upon the advice of people with knowledge of organizations in the disability community. While this does not constitute a representative sample and no concrete generalizations can be made, I thought it would be interesting to see if any regional differences were evident that would prompt further, more comprehensive study. As the study progressed, it became clear that it would no regional distinctions could be drawn.

Organizations have been chosen based upon an organizational mandate toward a form of community building that addresses both social and economic need within the target community. This community did not have to be geographically-based, rather it was key that the organizations be formed, to a large degree, around the basis of shared interests. It was also important for the organization to be committed to hiring people with disabilities and having at least 50% plus one of their Board of Directors comprised of people with disabilities. The organizations chosen had to have exhibited some form of experience (positive or negative) with the use of ICTs and to have been in operation since at least 1995. This was important because these organizations needed to have had considerable experience with the use of ICTs, but also be able to compare their work with work done before ICTs became such a central part of community organization. It was not, however, important that all the original staff were still employed, as long as there is sufficient organizational memory[112] to illustrate the organization's overall experiences. Since Dodge and Kitchin pinpoint the emergence of internet as we know it, with search tools, and modes of online communication such as Internet Relay Chat (IRC) as emerging in the early 1990s, it is reasonable to assume that organizations of persons with

[112] the records and accounts that document the history of the organization

disabilities would not have come on board with the Internet and the various modes of online communication until the mid 1990s.[113] Therefore, I looked from 1995 onward.

Key informant interviews were performed with 2 staff persons of each organization, with an effort made to speak with the leaders of the organization. Content analysis of key documents and the organizations' websites were conducted in order to add to the information gained through interviews. The interviews were transcribed and coded using Nvivo software. Grounded theory was used to develop an analysis of the research data drawing from many academic fields, such as sociology, human geography, politics, and disability studies.

4 Analysis of Data

4.1 Case Study Selection

The selection of case study organizations posed initial problems to the research. Above and beyond meeting the criteria of being organizations of persons with disabilities doing community development, an attempt was made when selecting the organizations, to have representation of organizations with varying levels of sophistication in the use of technology. A continuum was developed to measure the organizations' technological sophistication based upon models used for assessing institutional capacity by various non-governmental organizations.[114] While identifying organizations that met each stage of criteria was not difficult, obtaining their consent to participate in the study was more difficult.

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[113] Dodge and Kitchin 2001, p. 11

[114] VanSant, J. 2000. "Assessing the Capacity of Development Organizations," (Durham: Duke University Press) available online: http://www.ngomanager.org/dcd/2_Organisational_Development/Organisational_Assessment/

A perception scale was used to rank the chosen organizations based upon a series of criteria that described each stage. Organizations were initially ranked based upon initial assumptions and initial visits to the organizations' websites. After interviews were conducted with the organizations and more thorough content analysis was performed on the organizations' documents and websites, the continuum was revised and the organizations were ranked on the continuum again. This often changed the initial assessment and even pushed one organization into a higher stage on the continuum.

Organizations at what I would term the *nascent* stage of technological sophistication would have exhibited some use of technology, including:

1. the existence of an organizational website,
2. the use of e-mail and fax information for contacting the organization, and
3. links to organizations with similar interest on their website.

These organizations are using technology to a minimal degree, but it is not a deeply ingrained part of their day-to-day operations. Their websites are used primarily as one-way information repositories, where observers may come and access information, but provide no input back to the organization online, with the exception of e-mailing the e-mail address listed as a contact. The website would not be interactive or engaging in any way.

As nascent organizations become more sophisticated in their use of technologies they become organizations at the *emerging and expanding* stage. These organizations are beginning to expand their use of technology from the nascent stage by demonstrating a higher level of technological engagement with the members of their target community. This engagement, however, is often limited to self-help or online support groups,

members are still not engaged with the operation of the organization. At this level, organizations provide:

1. public access to technology in their offices,
2. training on different forms of technology and their uses, and
3. early forms of online engagement such as message boards or listservs,
4. programs dedicated to studying the effects of technology on their target community.

Finally, organizations at a *mature* stage of technological sophistication have thoroughly institutionalized the use of ICTs into their day-to-day operations and interactions with their target community. These organizations:

1. employ staff persons over distances that do a large degree of their jobs online,
2. organize meetings and conferences online,
3. have large amounts of their organizational budgets dedicated to the purchase, maintenance and upkeep of technology,
4. offer online service delivery including online training and workshops to their members,
5. offer substantial amounts of information online,
6. have highly developed networks of message boards, listservs and chat rooms,
7. engage their membership in the operations of the organization through online methods.

For example, the website, message boards and listservs permit the members to contribute their thoughts and ideas to the organization, who take this interaction to the next level by translating their input into projects and programs of the organization. This category is sure to expand as organizations at the mature level of technological sophistication continue to experiment with the use of technology.

It is important to note that there are no value-judgements attributed to each stage of technological sophistication. Organizations at each stage have very good reasons for

being within that stage. Some organizations do not have the time, resources or staff to devote to developing more sophisticated uses of technology. Other organizations do not place the use of technology at a high priority within their organizational mandate. They believe their time and resources are better spent elsewhere. Also, many organizations do not believe that sophisticated uses of technology are appropriate for the members of their target community. Either because they find technology too costly, inaccessible or irrelevant to their members, they feel that sophisticated uses of technology are not appropriate for their organization. Similarly, others feel that the technology is appropriate, a high priority and a valuable investment for their organizations and their members.

Difficulties with the selection of organizations for the case studies arose in trying to engage organizations at the nascent stage of technological sophistication. It was not difficult to identify these organizations, but when they were invited to participate, they either declined to participate or did not respond at all. Based upon their explanations and my own understanding of the organizations themselves, it would be reasonable to assume that they declined for a variety of reasons. For example, these organizations tend to be stretched for time and resources and therefore could not afford the staff time to devote to the study. They also may not have much interest in the study because of a lack of interest in technology in general. They may find it more useful to participate in studies that surround issues they deem to be of more immediate concern to their members, like housing or income support. For whatever reasons they may have had, the organizations I identified declined to participate.

It was also difficult to identify organizations that initially fell within the mature stage of technological sophistication. At the outset, none of the organizations I chose seemed to have reached this stage of sophistication in their use of technology. So while I began the research with what I believed would be organizations that fit within the emerging and expanding stage, after the research was conducted, I realized that one of the organizations was, in fact, using technology at a much more sophisticated level and moved into the mature stage of development.

4.2 Case Studies

4.2.1 St. John's Independent Living Resource Centre (ILRC)

St. John's Independent Living Resource Centre is a consumer controlled, not-for-profit organization committed to providing supports, resources and opportunities to enable persons with disabilities to make informed choices about their lives.[115] The Centre is located at 4 Escasoni Place in St. John's, Newfoundland. St' John's ILRC is a cross-disability organization, which means that they work with people with a variety of types of disability. They offer a range of disability-related information, resources and programs. The organization employs ten permanent staff positions, is supported by team of volunteers, and is managed by a consumer controlled board of directors. They receive core funding from their province's Department of Health and Community Services. In addition, they receive funding for individual projects from their federal counterpart, the Canadian Association of Independent Living Centres (CAILC), Newfoundland and

[115] www.ilrc.nf.ca

Labrador's Department of Human Resources, Labour and Employment, and from a joint federal/provincial initiative called the Community Access Program (CAP).

Principles that Guide the Organization

Consumer control is cited as the most important principle that guides St. John's IRLC. People that come to the organization to access information and services design the way that they access those services. Another important principle is that it is cross-disability in nature. This means that no matter what type of disability or impairment a person may have, they can become members in the organization and its board of directors, and feel that their concerns are important to the organization as a whole. Another important set of principles to the organization is dignity and risk. The organization believes that people with disabilities should be afforded the same dignity as other people in taking risks and accepting the responsibility for the choices they make. Just like any other person, people with disabilities must be able to take risks, make mistakes and learn from them. For too long, people with disabilities were protected by caregivers, institutions and society, considered too vulnerable to make decisions for themselves. The organization strives to support people with disabilities as they make choices and accept risks.

Defining Community

The organization's definition is both geographically and interest-based. The ILRC provides service to anyone with a self-declared disability in Newfoundland and Labrador. They are one of the only grassroots, cross-disability organizations for the province. However, as one person from the organization explained, "Who we serve as members is

pretty much anyone who gets in touch with us" (interview with representative of disability organization). Some services are only open to people with disabilities while some, like the resource library and CAP site, are open to the general public. They also have members outside the province who have been helped by the organization in some way and want to show their support through membership. Mostly, their membership is based on shared interests and values. According to one staff person, it is the organizational principles that continually attract people to the organization.

> It's the fact that the consumers that access services here at the ILRC design those services, they're the ones in the driver's seat of the thing. So they decide the speed, the direction and who's going to help them out with services? Is it going to be one on one with a coordinator or is it going to be setting up more like a peer atmosphere for themselves. A lot of people seem to be attracted in by that. (Interview with representative of organization)

Programs and Services

Individual Advocacy

There are two Individual Advocates on staff at the St. John's ILRC. They support consumers by identifying and accessing the various services they need. For example, advocates work with consumers to sort out difficulties with housing, social assistance benefits, Canada Pension Plan Disabilities Benefits, home support services, transportation, education, medical and rehabilitation treatment, educational supports, disability-related accommodations, etc.

Peer Support

The Peer Support Program is coordinated by a staff person of the ILRC and run by a team of volunteers. The program tries to bring together people who have had or are in similar situations to have fun, learn new things and discover their talents.

Information and Networking

The Information and Networking Coordinator can put consumers with disabilities in touch with the information or contacts they require. Most consumers' initial contact with the organization occurs through the Information and Networking Coordinator. They offer information sessions about the ILRC and the Independent Living Movement, facilitates workshops, and assists students, businesses, and other agencies and government departments in finding the disability-related information they need.

The ILRC believes that "information is power" and that people with disabilities themselves hold the most accurate and up-to-date information and knowledge. The Information and Networking Coordinator gathers this information and shares it with people in the community by hosting information sessions and presentations at community groups and schools.

The organization also hosts a resource library with books, magazines, newsletters, reports, assorted videos, audio-cassettes, Braille and CD ROMs on a variety of disability-related topics.

Full Steam Ahead and Navigating the Waters

There are two Career Development Facilitators for the two employment-related projects at the ILRC. The Full Steam Ahead program helps with individual employment needs, which entails exploring the idea of work and learning in a way that's comfortable to the consumer. The Navigating the Waters program also helps with career development by placing consumers in volunteer positions to help them develop skills and make career choices that can often lead to employment. They assist consumers with: workplace

accommodation, resumés and cover letters, barriers and problem solving, employment advocacy, interview skills, goal setting, job searching, and finding funding.

Community Access Program (CAP)

The St. John's ILRC hosts a government-sponsored Community Access Program site. The CAP sites is hosted in a barrier-free room, complete with computers, internet access, office software, printers, a scanner and many types of adaptive software and hardware. Their goal is to remove the barriers that come with technology and become a "Centre of Excellence in Adaptive Technology". They have large screen monitors, text enlarger programs, height adjustable workstations, Dragon Dictate (a voice input program), JAWS (a voice output program), ergonomic chairs, page readers, a digital keyboard, touch screen monitor, Zoom text, Juliet Braille Printer, Kurzweil Reader, Joust2 Sip and Puff, adaptive keyboards, digital cameras, printers, and a scanner.

4.2.2 National Network for Mental Health

The National Network for Mental Health is a national disability organization that is 100% consumer driven. All board members, voting members and most staff are mental health consumers/survivors. The organization began at the Canadian Mental Health Association's "Consumer Participation Task Group" in the 1980s and became independent in 1991. The name changed and they became incorporated in 1992. Their offices are located at 55 King Street in St. Catharines, Ontario. The purpose of the organization is to advocate, educate, and provide expertise and resources that benefit the

Canadian consumer/survivor community.[116] They also network with Canadian consumer/survivors to provide opportunities for resource sharing, information distribution and education on mental health issues. The organization focuses on trying to create "programs that focus on building the capacity of individuals through education, employment support and inclusion."[117]

Principles that Guide the Organization

The organization holds, at its core, the principles of informed consent and inclusion. Informed consent means that people with disabilities have the right to the education, information, and resources needed to make choices about their lives and should be afforded an equal ability to do so. Inclusion means that people need to be included in policy and program development, be afforded skill development opportunities, leadership training and tools in place for them to participate equally in society. Equality is another important principle for the organization as all people have the right to expect privileges granted to them by the Canadian Charter of Rights and Freedoms. The organization also promotes respect of the value of others as contributing members of society and should be utilized as such when there is ability to do so, including incorporating their input in policy decisions of the government.

Defining Community

The organization defines community as being people with similar backgrounds, who face similar issues, and have similar goals and objectives as one another. To NNMH,

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[116] Flatt, J. and B. Pape. 2003. "Stronger Together: Steps Toward a National Mental Health Network," in D. Stienstra and A. Wight-Felske. 2003. *Making Equality: History of Advocacy and Persons with Disabilities in Canada.* (Concord: Captus Press)
[117] Ibid

this means that their community is made up of mental health consumers across Canada. They identify themselves as part of the larger disability community in Canada as well as part of a various social movements, including the disability rights movement and the mental health consumer movement. This definition of community is based upon shared interests and values as their members must agree with the principles that guide the organization. In fact, to become an official member with the organization, one must sign a written declaration that one agrees with the organization's principles.

Programs and Services

Opening Doors, Building Employment Capacity for Mental Health Consumers Nationally

The 'Opening Doors' program is an innovative consumer-driven project designed to provide information, advocacy, support, educational opportunities, skills development, and assistance to participants. Participants in the program develop personal and professional capacity and move toward employment to reduce reliance on income support.[118] The program is funded by Social Development Canada's Opportunities Fund and has been in operation since 1997. There are five projects sites, located in St. Catherine's, North Bay, Moncton, Winnipeg and Calgary.

Consumers in Action (CIA)

The Consumers in Action project is a three phase project designed to enhance the capacity, advocacy and leadership skills of mental health consumers in Canada. Retaining leadership is a difficult task for most organizations in the disability community, but the mental health consumer movement has found it to be a very difficult challenge. This

[118] www.nnmh.ca/project.html

program works toward building new community leaders through capacity-building and skill development. They address past challenges by teaching advocacy skills to their consumers and by making people aware of their citizenship rights.

BUILT Network, Customer Service Representative Program

The purpose of the BUILT program is to provide life skills, coping mechanisms, customer service and computer skills to participants with mental health issues and disabilities. The seven week program aims to support people with low self-esteem, self-confidence and who have experience depression or other mental health concerns that may be affecting their ability to obtain and retain employment. The project employs small groups to allow for more one-on-one time for individuals. A representative of the program said,

> The project sites are so successful because the project staff are right there, in the program with them 100% of the time, so that if someone is having an issue or having challenges, you have support right there. (interview with representative of disability organization)

One way they facilitate this is by overcoming people's fear of failure by offering a version of the project online, with real-time live instruction that allows people to take the course regardless of where they live or what type of impairment they may have. An instructor is available at set times to meet with the participants online.

The program helps participants develop a solid set of personal and professional goals. The online version remembers their affirmations and reminds them of why they are taking the course and what their goals are as soon as they log onto the site. Employer, business and volunteer guest presenters provide participants with information about hiring policies as well as information about employee activities and responsibilities.

Employment opportunities upon completion of the project include, but are not limited to, office work, retail employment, data entry, hotel/restaurant administration, shipping/receiving, or employment in a call centre.

Participants acquire basic computer skills, sales training, resumé and cover letter development, interview skills, work ethic development, communication skills, and teamwork skills. They develop self-esteem and confidence to pursue their desired level and place of employment.

4.2.3 National Educational Association of Disabled Students

The National Educational Association of Disabled Students (NEADS) is a consumer organization that advocates for increased accessibility of post-secondary institutions and programs so that students with disabilities can have equal access to college or university education. Their mandate is to encourage the self-empowerment of post-secondary students with disabilities, which allows for broad interpretation of their goals. The association provides information and programs, publishes a newsletter, conducts research and lobbies for change at the political level. The organization is governed by a 12 person Board of postsecondary students with disabilities.[119]

NEADS was started by a group of students who were members of *Awareness Carleton*, a club for disabled students at Carleton University in Ottawa. NEADS developed according to the principles of the disability rights movement. The goals of the organization include expanding a communications network for students with disabilities and those involved in support programs for disabled students at colleges and universities across Canada. The organization strives to make timely and meaningful responses to the

[119] www.neads.ca/en/about/

issues and concerns affecting the educational resources and environment of disabled students.[120] They also strive to facilitate information collection and distribution on topics of relevance to the organization and its goals. The organization also encourages students with disabilities to form their own groups and societies to advocate on their own behalf.

Principles that Guide the Organization

NEADS is a cross-disability organization, serving the needs of disabled students across Canada regardless of the nature of their disability or impairment. They are a consumer-based organization, which means that the majority of their members are people with disabilities and that they are governed by a Board of students with disabilities. They are also driven by the principles of access, inclusion and equality, advocating these rights for students with disabilities, in particular.

Defining Community

NEADS is an interest-based organization that defines its community in many ways. Their constitution and by-laws dictate the requirements for official membership in the organization. There are four levels of membership in NEADS:

- Regular members are disabled students at the post-secondary level, disabled people who have participated in a post-secondary program within two years of applying for membership or an authorized persons acting on behalf of a disabled student. A regular member must be a Canadian citizen or a landed immigrant.
- Associate members are anybody interested in the objectives of the organization.
- Institutional members are organizations, businesses or post-secondary institutions interested in the objectives of the organization.

[120] Ibid

- Honorary members are people recognized by the Board of Directors. Terms and conditions of membership are determined by the Board of Directors for each honorary membership given.

While the constitution and by-laws dictate official membership in the organization, NEADS considers itself to be part of many communities with similar interests. They are part of the post-secondary community in Canada, which is made up of colleges, universities, student groups, and research bodies dedicated to improving the level of education available in Canada. They are part of the broader disability community in Canada through their membership with the Council of Canadians with Disabilities and associate themselves with both the disability rights movement and the student movement in Canada. They also seem themselves as servicing other communities made up of student groups, other disability organizations, student unions, service groups and employers. NEADS networks with all of these groups in order to fulfill the goals of the organization. NEADS also sees its role as building community by providing linkages between many of the above-mentioned groups.

Programs and Services

Inclusion of Students with Disabilities in College and University-Sponsored Activities

This project, completed in March 2005, examined how accessible college and university extra-curricular activities are for students with disabilities. Funded by the Government of Canada's Social Development Partnerships Program, the project focused on new student orientation, student elections, and campus clubs and organizations.

Project staff worked with staff and students of the institutions as well as surveying students to obtain all possible perspectives. The project produced a report that highlights best practices and identifies opportunities for improvement.[121]

Access to Academic Materials for Print-Disabled Post Secondary Students

This project represents a partnership between NEADS, the Learning Disabilities Association of Canada (LDAC) and the Council on Access to Information for Print-Disabled Canadians to implement a study to improve delivery and access to academic materials for print-disabled students. The project, completed in April 2004, was funded in part by the Government of Canada's Social Development Partnerships program. NEADS was the lead organization, implementing the objectives of the project, managing the project and producing reports. The goal of the project was to provide French and English students with access to materials in alternative formats. The project produced detailed report that shows how services and materials can be better coordinated and used, identifies significant gaps in the of supporting students needs, and recommends next steps to be taken and put into context. The project was guided by a steering committee of users and service providers. The project has been completed and the report is available on the organization's website.[122]

NEADS Student Leadership and Employment Forums Initiative

This project has hosted a series of six student leadership forums across Canada, starting in 1998. The goal of the project was to strengthen the links between NEADS and

[121] You can access the report at: http://www.neads.ca/en/about/projects/inclusion/guide/
[122] http://www.neads.ca/en/about/projects/atam/

the network of groups on campuses across Canada. The organization plans to continue these forums as the project was considered a success. The forums have brought to the fore some of the driving issues and concerns of the organization and are used by the organization to keep in touch with the concerns of its membership. A series of publications and reports that have resulted from the forum are available on the website.[123]

CampusNet

CampustNet is an online initiative that strives to be a "uniquely Canadian online collaborative community bringing together campus-based organizations of students with disabilities."[124] CampusNet is an interactive online forum where information on projects, approaches, techniques, and challenges can be shared.

High School Outreach Project, "Moving On"

This project responds to an interest of NEADS' members to reach out to students with disabilities still in high school. The project received funding through the Government of Canada's Social Development Partnership's Program. The project has three main components.

1. The development of a transition guide for students with disabilities going from high school to post-secondary institutions.
2. Connecting students with disabilities in high school connect with NEADS online.
3. Holding focus groups with students with disabilities in high school to advise the development of the transitions guide and to add to content on NEADS.ca

[123] http://www.neads.ca/en/about/projects/student_leadership/
[124] http://www.neads.ca/campusnet/en/

NEADS sees this project as advancing its mandate by incorporating proactive and preventative measures to ensure that the transition process from high school to post-secondary education is as smooth as possible for students with disabilities.

National Directory of Financial Assistance Programs for Students with Disabilities

With funding from the Government of Canada's Social Development Partnerships Program, NEADS is developing a reference source of available funding to disabled students for post-secondary study. The directory will provide a comprehensive source of information on financial assistance in one document written in plain language.

NEADS Online Resource Centre (NORC)

The NEADS Online Resource Centre is comprised of several online components. One such service is EdLink, a directory of disability service providers at Canadian colleges and universities and their contact information. Another project is the CampusNet project described above. NORC also includes the NEADS Online Work System (NOWS), a service that allows post-secondary students with disabilities to promote their skills and talents to progressive employers seeking candidates with disabilities for available positions. Opportunities include summer, part-time work, internship programs and full-time careers. The NEADS-L network, a listserv offering an opportunity for anyone interested in the work of the organization to participate in online discussions, network and learn from one another, is hosted through York University.

4.3 Research Findings

4.3.1 Community Development

There are many forms of community development. Debates concerning community development have focused on urban planning of geographic communities, the knowledge and competencies of activists and the socio-spatial meaning of geographic space.[125] However, the organizations that form the basis of the case studies in this project pursue a type of community development that focuses mainly upon capacity building. *Capacity building* is a form of social capital development that aims to "activate localized social networks in order to mitigate the impact of social exclusion."[126] These activities aim to increase the ability and skills of individuals, groups and organizations, to plan, undertake and manage initiatives. This often entails employment and skill development, political engagement, and society-wide community awareness programs.

Employment

Each of the organizations has some form of employment-related projects. St. John's ILRC has two employment-related projects that focus on skills development. The National Network for Mental Health has a project called the BUILT Network, which stands for Building Up Individuals Through Learning and Teamwork. This project focuses on personal and professional development, customer service, personal sales, computer and interview skills. NEADS Online Work System provides students with disabilities with job opportunities, including internships. The NEADS Online Work System enables hiring companies to post employment and internship opportunities specifically for qualified Canadian post-secondary students and graduates with

[125] Shirlow, P. and B. Murtagh. 2004. "Capacity-Building, Representation and Intracommunity Conflict," *Urban Studies*, 41, 1, p. 57
[126] Ibid, p. 59

disabilities. Students can upload their resumés, browse and search for employment opportunities, and apply online. Opportunities include summer, part-time work, internship programs and full-time careers. The last time I checked their website, they had 793 registered students and graduates with disabilities registered on their site.[127] They had 51 registered employers representing 15 different industries.

Employment can be empowering for people with disabilities. Being able to participate in the workforce is a vital part of the independence necessary to allow people with disabilities to participate as full and equal members of society. Building people's capacity to find gainful employment is an important part of community development.

Political Engagement

All of the organizations studied in this research engage in some form of political engagement. They try to engage their members in the political process in many ways. This often includes campaigns to raise awareness of political issues among their membership to encourage them to embrace their citizenship rights through voting, lobbying and other forms of political engagement. The representative from St. John's ILRC tells of how technology has increased their organization's effectiveness in political lobbying campaigns. This person described how quickly the organization can now engage their membership in political action as it happens and how quickly letter-writing campaigns can be organized via e-mail or the web when an issue quickly arises. One of the representatives from NEADS spoke to how the use of listservs and message boards can keep the organization abreast of the issues that concern their membership. He said, "People raise issues that we, maybe are not addressing as an organization. And from that

[127] Accurate as of June 25, 2005

it helps us develop our organizational work and our priorities in the same way that our national conference does..." by giving the members a forum through which to express their concerns.

The Disability Rights Movement is often referred to as a New Social Movement (NSM). As explained by one of the champions of new social movement theory, Alberto Melucci, NSMs are distinct from previous forms of collective action because they form the basis for new types of popular resistance, consisting in the mounting of "symbolic challenges which publicize novel dilemmas and problems, the clarification of which requires new definitions of freedom and the recognition of new rights and responsibilities."[128] In contesting the institutionalization of people with disabilities, early leaders of this movement promoted a new type of freedom for people with disabilities by developing new models, theories and philosophies about the rights and responsibilities of people with disabilities. The social model of disability, the Independent Living philosophy and various other theories discussed in the literature review portion of this thesis were promoted by the movement in an attempt to move beyond more traditional forms of collective action, toward cultural and political praxis that changes not only how governments, but also how society views the rights of people with disabilities.

Community Awareness Programs

Each of the organizations studied for this research engage with the rest of society to create awareness about the needs of people with disabilities in their communities. Sometimes this takes the shape of awareness-raising and sensitizing people to the reality

[128] Melucci, A. 1989, *Nomads of the Present: Social Movements and Individual Needs in Contemporary Society.* (Philadelphia: Temple University Press), p. 11

of how society erects barriers to the participation of people with disabilities in social, economic and political life.

Each of the organizations has someone on staff to give presentations at conferences, do workshops for businesses and schools, and engages with postsecondary institutions and other research centers to add a disability-perspective to various bodies of research. They have reference libraries both on site and through information available on their websites. They circulate newsletters and other forms of disability media to inform their communities and the general public about issues that affect the lives of people with disabilities. Two of the organizations studied referred to this as "capacity building". They believe that educating the wider public about disability issues builds the capacity of their community for social change, by broadening their base of support and by educating the public about the work they do. This helps to bring new people into the organizations and helps make the broader public, including potential employers, government and other activists aware of the implications of their actions and attitudes on people with disabilities.

Capacity building is an effective form of community development for the disability community for a variety of reasons. It is particularly effective because of the way in which they define 'community'. Much of the community development literature treats 'community' uncritically and as a distinctive and unitary concept and, for the most part, focuses upon the importance of geographically defined areas.[129] In contrast, the disability community defines 'community' on the basis of shared interests, or collective identity, rather than on location or geographic space, characterized by personal intimacy, moral commitment, and social cohesion. This type of definition is more conducive to

[129] Ibid, p. 57

capacity building through empowerment, defined in the literature as "a process that occurs both at a personal and political level and involves changing power relations between individuals and groups and social institutions."[130] This is problematic in communities defined geographically because, as Edward notes, empowerment assumes the existence of a unitary set of values and interests.[131] While this assumption is not necessarily plausible in geographically-based communities, the organizations in the disability community define their sense of 'community' on shared interests and values. This is more conducive to the empowerment of their members and to overall community capacity building.

When asked how they define community, the organizations in the case studies said that their communities are based upon shared interests and principles. For the most part, the principles that guide the organizations were all similar, which facilitates their broader connection as a movement. For example, all of the organizations emphasized the importance of consumer control in all aspects of the organization. All but one of the organizations was cross-disability in nature, which means that they serve any person with a disability regardless of the nature of the impairment. The other organization focuses mainly upon mental health concerns, while still acknowledging that many people with mental health concerns may have other types of disabilities as well. Principles like inclusion, respect, and informed choice are the principles that bind these organizations into a community.

One organization's representative said that the principles that guide their organization are what attract people to them. They identify their community in the same

[130] Shragge, E. 1993. Community Economic Development: In Search of Empowerment. (Montreal: Black Rose Books)
[131] Edwards, J. 1997. "Urban Policy: The Victory of form over substance," *Urban Studies*, 34, p. 825-43

way that they define their membership, but they also identify as a larger disability community, in reference to their participation in one or various social movements, such as the disability rights movement, students movement, mental health movement, women's movement and the Independent Living movement.

4.3.2 Implications for Practice

The research has resulted in new knowledge about what makes community development organizations of people with disabilities unique players in the knowledge-based economy. While the inherent values of capitalist development may clash with the goals of these organizations there is still potential for organizations to make ICTs work for them in real and exciting ways.

In particular, this research brings to the fore some of the various forms of computer-mediated communication that organizations around the world are already using to further their community-building efforts. The women's movement, the human rights movement, the anti-globalization movement, and many others have already embraced online communication as a way to bring together communities of people that may be dispersed across large geographic spaces. These are communities not formed because of a geographic locale, but out of common interests or beliefs. By looking at the experiences of the women's and other movements, we can understand how organizations in the disability rights movement can operate more effectively using these technologies.

4.3.3 Use of Computer Mediated Communications

When asked for information regarding the types of ICTs used in their day-to-day operations, all organizations referred to the use of telephones, fax machines, e-mail and

websites. One organization mentioned TTY access for the deaf and hard of hearing, and while others did not mention this form of communication, most of them employed the technology. When asked about the types of technology used rarely or for special purposes, they mostly mentioned message boards and listservs as well as unique types of online management and organizational tools (discussed in the section about Internet Relay Chat and Instant Messaging below).

E-mail and mailing lists

The speed, relative reliability, cost and ease of e-mail makes it a particularly effective mode of communication for people with disabilities for whom issues of time and space have more complicated meanings. As Hansen notes, "There is limited understanding of the disabled person's organization of time and speed factors associated with disability or impairment so as to function effectively in daily life."[132] As Hansen points out, managing time, speed and personal energy levels is a constant balancing act for many people with disabilities. For this and other reasons, e-mail can be an effective mode of communication for the disabled, even more so than the non-disabled.

Relatively simple to use and compatible with most assistive technology, e-mail allows organizations to keep up with global issues and campaigns, to disseminate information through files, pictures and video, and can multiply, exponentially, the amount of people that organizations can be in contact with on a regular basis. While there are many positive aspects to using e-mail and mailing lists for communication, there are also draw-backs. Every organization I worked with for this project said that e-mail has broadened the scope of their organizations by increasing the number of people they keep

[132] Hansen, 2002, p. 6

in contact with on a regular basis, but also by increasing the number of people that contact them. Every person I spoke with talked about coming back to the office after a day or two away, to find themselves barraged by an overload of work as a result of e-mail. They cited numbers as high as a hundred e-mails a day. They referred to an "overdose of communication" resulting in more work, increased stress, and lost time that could've been spent elsewhere. One person said that as the speed of computers and internet connections increase, so do the speeds at which organizations are expected to work.

> We've gone from the slower computer and the slower dial-up to the fast speed computers and fast speed connection and of course that's a pleasure because we're not drumming our fingers waiting for something. We've got it right now. Correspondingly, we work faster. That brings more stress. We do more in a shorter period of time and I think that's everybody. More in a shorter period of time, and there's an expectation, sometimes that we should be getting instantaneous responses. Like, 'Why didn't you get back to me in an hour?' 'Well I was in a meeting with a bunch of people in a room, not sitting at my computer.' (interview with representative of disability organization)

One representative said that it was not only others' expectations that increased, but that internal expectations of the amount of work one does increases as well. They likened it to an imaginary conscience.

> Do you remember on the *Flintstones* there used to be this little Martian called 'Gazoo'? He used to fly around and hover over people's shoulders. It's like there's a little Gazoo over everybody and we all want to become better, more efficient, faster...so I think there's expectations from within, never mind without your supervisor, coworkers...We all have this little Gazoo inside of us that's always saying, 'Ok, how much more can you get done today?'...So I guess internal expectations are high. (interview with representative of disability organization)

A representative said that they believed that e-mail creates unhealthy work situations for individuals because there is added pressure on people to constantly keep up.

> With the advent of e-mail…it has made life easier to some extent but it really has disabled a number of organizations and people from focusing on what they're really doing, because you get so much communication in a day...it really does have a negative impact, overall on your mental health. (interview with representative of disability organization)

The organizations acknowledge that there is a delicate balance between technology's benefits and the traps into which people can fall. It seems as though the drive to be more efficient and get the job done quicker is only creating more work to do. One representative gave an example of the tensions.

> Today I was at a committee meeting, I came back and there was a very fast e-mail from one of the Executive members to the rest of us that are on the Executive that spun us out into a thread so that we were almost talking together, we were responding so quickly. It meant that we dealt with something right away, but it also increased the work because we'd already been out to a meeting, we came back and then sort of continued it. So on one hand, we were continuing the work which was great, but on the other hand we all had other things to do, but got into this loop of talking to each other by e-mail, which means that somebody's staying late today to finish something else. (interview with representative of disability organization)

Similarly, another representative said that for some things, e-mail is not easier than using the phone.

> There are some instances where it's better to talk to someone on the phone, for example, then to e-mail them. Simply because you do a lot of back and forth. E-mail's great, but it has its limitations. You do a lot of back and forth with e-mail, whereas sometimes if you just pick up the phone and talk to someone for ten or fifteen minutes, you can sort out a problem that might take five or six e-mails back and forth. You need to use all of the methods of communication at your disposal. (interview with representative of disability organization)

Balancing between the use of e-mail and the phone can be an effective solution. One person noted that while most people are moving toward the use of e-mail, it is important to use the phone to reach some people.

> When I started on the Board, I did a lot of stuff by phone...picked up the phone and called people. As things move on, you could really see the trend towards more e-mail. Is that a good thing? Yes, for people who check their e-mail regularly, but I always still coach our Board...to pick up the phone and not always depend on e-mail, because with the amount of junk mail people get and the amount of e-mail people get for school and work, it can be overwhelming and people will prioritize...and you can see the results of that sometimes, because people are not always up-to-date with certain activities. (interview with representative of disability organization).

One representative was concerned that when working with consumers who may be going through difficult situations, e-mail can bring a false sense of sincerity. For example, this person stressed the importance of sitting down and having a cup of coffee with a person. They said,

> The whole thing, about people in crisis, or people going through very stressful times...It's not what people say to you that gives you the support, it's the fact that people are there and they're listening and that they're engaging with you. E-mail can bring a falseness to that. (interview with representative of disability organization)

They believed that even a telephone conversation was more effective in these instances than e-mail or other forms of online communication. Like most of the organizations, they stressed the need to have multiple forms of interaction. They believed it was important to offer more than one kind of interaction to an individual. In fact, their practice is to make initial contact with the individual by e-mail, then to follow-up by telephone, and then to have a face-to-face meeting. They said that only in person or on the phone would they be able to establish the kind of trust that would make an individual bring up more issues than

they would by e-mail. They compared purely online communication to trying to access services through purely automated systems. You might eventually get what you need but you will end up incredibly frustrated.

Many of the people I spoke with said that it was important to continue to provide the more traditional modes of communication that people are used to like traditional mailings or flyers advertising events. One person stressed the importance of using traditional mail, saying,

> I'm the biggest techie you'll ever meet...but I'm always sensitive to the fact that for every email we send out letting people know about an event, and if we just use email as our means, there's probably like five to ten people who could benefit from that event who won't hear about it because it's an email.

They also indicated that there are just as many problems with the more traditional forms of communication as well. They said, "Again, how effective is a flyer if it's faxed to a disability services office where they're getting piles of other stuff? Or how effective is a flyer if it's posted up but it's not in Braille?" (interview with representative of disability organization)

While e-mail has reduced the cost of mailings significantly for the organizations, it is important to many people to continue to have a choice. However, one person found that governments and other funders fail to acknowledge the continuing importance of this medium of communication. They said, "[Continuing with traditional forms of communication] becomes a burden as well because when we go and ask for dollars for funding, governments expect that everyone can access online. So they cut different [budget] lines."(interview with representative of disability organization)

With that said, many of the organizations still believe that e-mail makes their jobs easier overall, is cost-effective for the organization, and is a convenient form of communication for their members. One representative, who had been in his position for almost 20 years, related how technology has made their work easier.

> When I started in this organization, we were using typewriters back then. Even fax machines were a fairly new invention. You had to courier things to people. Now we send e-mails with attached files, back then we'd have to use a courier to get a document to somebody within a day or two. (interview with representative of disability organization)

Several people that I interviewed said that e-mail and message boards have created more and different ways to share information with their members and that added choice means greater accessibility. One representative said that their members are asking for more and more information in an electronic format, whether it be posted to the website or attached to the body of an e-mail.

> A lot more folks are moving towards wanting the information in an electronic format. What some of these people do with it, I don't know, are they using screen readers, is it just a preference for them to read it off a screen themselves or you know, producing their own Braille? I'm not sure. (interview with representative of disability organization)

This person went on to say that they prefer electronic copies as well, mainly for reasons of convenience and organization. They felt that if they received paper copies of documents they would lose them, whereas electronic copies are easier to organize.

Organizations also need to be sure that their members have access to computers and the internet, as well as the training and skills involved with accessing e-mail. As one person pointed out,

> Most people with disabilities...don't have access to a computer. Or know where to get access to a computer. So what we need to do is

> let them know where they can go access a computer. We do a lot of work with other CAP [Community Access Program] sites, public libraries, schools... in providing technology as well as working with people with disabilities, [who are] saying, 'we're just as much a part of this community so we have a right to access it too.' (interview with representative of disability organization)

Their organization attempts to address lack of access to the technology itself in many ways. In addition to simply having a CAP site, the organization also takes part in Industry Canada's Web4All program, which provides various types of assistive technology within the CAP site as well. The organization also offers sporadic workshops on computer training, including how to take apart a computer and put it back together, or how to build your own computer out of donated spare parts. Offering these workshops has been a positive experience for both the staff and consumers because it helped people overcome their fears of computers. The person who facilitated the workshop said,

> It was one of the best workshops because it really demystified computers as being scary, and intimidating. A lot of people were afraid to use the computer because they might break it, and it really showed how durable these things really are. (interview with representative of disability community)

It also created more access to technology because people began to drop off old computers that were used to obtain parts to put together new systems. People who have taken the workshop can come in, obtain the parts and build themselves a computer. They also keep a couple of CD burners in the CAP site so that people who don't have an internet connection (or a very fast one) can come in and download free software, burn it on a CD, and take it home.

The workshop is also considered beneficial because it gives people choice, one of the main principles that guides the organization.

> I think if more people were in the driver's seat where they could pick, 'I like this computer, I like this keyboard, I like this program and I also like it working with this program.' If they had that initial investment in picking out what's going to work best for them, they seem more [interested in technology]...'I made this system, it's mine, I customized it for myself.' (Interview with representative of disability organization)

Organizations also need to address that the costs associated with using e-mail are broader than simply having a computer in their home. Connectivity costs a lot of money and many people with disabilities do not have adequate income afford the costs involved.[133] One representative outlined some of the issues that organizations need to be sensitive to.

> It [technology] seems to have been a real benefit. Where there are difficulties is for folks who have barriers to that technology that they have to overcome because the technology's not inclusive. If you're blind and you don't have JAWS [a screen-reader program] you're not going to be using a computer and how do you get the funding for JAWS? If you can't afford the Internet and you have barriers to transportation... so you can't afford to have it at home, although you have a computer somebody gave you and transportation is expensive to get somewhere where you can use a computer...I think there are certainly some barriers for folks that lead to some frustration because there is stuff out there they want to do and want to take part in, or want to have access to that there are barriers to. When people resolve those barriers, it seems like it's a benefit for everybody that wants to participate. (interview with representative of disability organization)

One representative said that the use of e-mail has allowed them to network and work with other organizations in much more sophisticated ways than in the past. In particular, this organization gets much more sophisticated requests for information than in the past, because organizations from all over the world can contact them via e-mail. They participated in a research project on home supports with a University in Bulgaria

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[133] Social Development Canada. 2004. *Advancing the Inclusion of Persons with Disabilities*. (Ottawa: Government of Canada)

because they were contacted by the researchers by e-mail. The representative said, "It never would've happened if they were using phone, but because we're all out there on the Web, it was able to happen that way." (interview with representative of disability organization)

Another person said that technology and the use of e-mail in particular, has enabled their organization to produce more sophisticated types of documents and share information in more complex ways.

> It's made things easier, it's made people more efficient. And it means we can do more work, we can take on more ambitious projects, everything happens faster. For example, we just finished this...300 page report with lots of charts and tables and graphics and things. We couldn't have done that, even ten years ago, we couldn't have produced it without technology. And consultants working on a project can communicate more effectively with one another when it comes to reviewing drafts of reports, for example, and editing them. Because of the efficiency of online communication, we can share reports through the internet and get people to review documents and edit them...The whole thing's more efficient. (interview with representative of disability organization)

Not only does e-mail facilitate organizations' ability to network with other organizations and engage in more sophisticated activities than in the past, it also changes the nature of how organizations work with their staff members. Most of the organizations said that they did not think that technology has affected their ability to employ people with disabilities because they were already doing that (all of the organizations were mandated to employ people with disabilities as at least 51% of their staff members). However, all of the organizations said that technology, especially e-mail, enabled them to work with people with disabilities in different ways. For example, technology might

enable a staff person to do different and more types of work within the organization. It might also facilitate different types of employment, such as home-based work.[134]

The people I spoke with had varying opinions of home-based work. One representative had a very negative opinion of home-based work, but supported it if it was the individual's choice. This person said that their organization has offered this as a choice to people, but that for the most part, people don't want to work at home. They believed that too often organizations, businesses and government pressure people with disabilities into home-based work to save on costs.

> We haven't made anyone work from home because of technology, because sometimes that's exactly what technology is used to do. It isolates people. You don't have to pay office space, you don't have to be nice to people, you don't even have to have them near you, just give them a job and have them work from their corner of their bedroom or their space bedroom. Certainly the federal government and some companies are really good at that. And I think that can be really abusive sometimes, personally. Because people don't have the collegial atmosphere, they don't have colleagues, they don't have immediate supervisors to have a face-to-face conversation with. They're just expected to operate almost in isolation. It works for some people, it's often touted as a really good thing for people with disabilities because, after all, they wouldn't have to leave their house to go to work. My knee-jerk reaction to that is, how sad and how awful, that you're considered that it's better for you not to have to leave your house...It would be horrible, unless, of course, if it's someone's choice. But when it's not by choice, I think it's really bad. (interview with representative of disability organization)

Another organization had a very different opinion of home-based work. This organization offers home-based work to people that they otherwise would not have been able to hire either because of the nature of the person's disability or because of geography. Many of the people employed by the organization as consultants are based all

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[134] Canadian Centre on Disability Studies. 2002. *Best Practices in the Home-Based Employment of People with Disabilities*. (Winnipeg: CCDS)

across the country and work for the organization from their homes or offices in other cities. In this case, the use of e-mail has facilitated the employment of people with disabilities based upon their skills and abilities rather than their location. The person was careful to note, however, that home-base work should not be done in isolation. The organization makes certain that they have regular face-to-face meetings with their consultants.

> Now… regardless of somebody's disability, or where they're situated, if they're good at what they do and they have the skills and the equipment at their disposal, then you can work with them wherever they are, wherever they're located…[but] I think you have to have a little bit of both. You still have to have face-to-face meetings with people and you still have to talk to them on the telephone. People can't always be working virtually. (interview with representative of disability organization)

E-mail is only more effective if it doesn't create extra challenges for the people the organizations are trying to work with. The organizations interviewed for this study appear to be taking the needs of their consumers into account when designing their technology, with some exceptions. One person interviewed had been planning elaborate use of online technology without the consideration of whether or not the program could be accessed with a screen-reader. After the interview, they planned to have it tested for all levels of accessibility, but it was alarming that an organization working with people with disabilities would not have considered this level of access. Another person had never heard of the Community Access Program (CAP) before. They had simply assumed that people were obtaining technology from other organizations in order to access their programs and services that are offered mainly online. I found it surprising that an organization that offers a lot of online services and communicates heavily with their members by e-mail hasn't given any real consideration to where their consumers are

accessing technology. The more I thought about their level of technological sophistication, however, I realized that their experiences with technology did not necessitate a concern about access. This organization still uses more traditional methods of communication along with the use of ICTs and has never experienced a situation in which someone came to them with concerns about access. While one representative said he expressed concerns that there may be people who cannot access the work they do online, he admitted to not knowing how the people that do engage with them online access technology.

Websites

Websites can be a powerful tool for community organizations. Websites can help organizations advertise their programs, communicate with members, disseminate information, and gain feedback from the community. However, websites present challenges in and of themselves.

It takes a lot of time and resources to create an effective website. Organizations that fail to apply a strategic approach to their website development risk alienating their users, building a weak foundation for their website, and miss opportunities to take advantages of ways to fulfill critical goals for the organization.[135] One of the organizations had a paid webmaster as well as a very committed volunteer who worked at least 12-15 hours per week on the organization's website. This person said that,

> If you don't have this kind of structure in place, whether it's paid or not, for the websites, you can usually tell where there might be issues because there isn't the level of support or resources to support a website or a listserv...because it does take time. It's not something you can just put up. (interview with representative of disability organization)

[135] Leverus, 2004

Many of the organizations did not have the expertise or knowledge of technology at the time their website was created to do the job themselves. One organization made reference to a government program called Indie that created basic websites for organizations that did not have them with the requirement that they must be "disability-related and relevant to the community of persons with disabilities."[136] Indie stands for Integrated Network of Disability Information and Education, a Canadian web site that centers on its goal to be "the world's most comprehensive one-stop resource for products, services and information for the world-wide disability community."[137] This program hosted their website and did its initial design, while the organization contributed the content.

Having the website created outside the organization often means that someone from outside of the organization, often with little or no knowledge of the goals of the organization or the needs of its consumers, did the initial design and creation of the website. Most organizations said that their web design has changed dramatically since it was first put up. Often the site was redesigned by someone on staff or someone hired to be the organization's webmaster. One person said that the impetus for the website's redesign came when they were first employed by the organization. They only had dial up at home and found that accessing the organization's website was very time-consuming.

> I just had dial-up and [the website] just took so long to load up on the page. Which made me think, oh my god, all these people with dial-up [would be having difficulty]. There was this banner on the page and it was made up of thousands and thousands of graphics that... look[ed] really small on the screen but they were actually really big. The pixels were set really high. And it just took forever to load up and on older computers you get these lots of little x's down the screen because not a lot of them would load up on the screen....We found ten tips on how to make your web page

[136] http://www.suite101.com/article.cfm/378/9867
[137] Ibid

> accessible and we stuck to that as closely as possible. So everything is very text-based on our page, even the graphics are based on text as opposed to being true graphics. (interview with representative of disability organization)

In this sense, many people employed by disability organizations are forced to become accessibility experts and teach themselves how to make a website accessible. Most often, this is part of a person's larger job description, or an add-on to the work they are already doing. One person joked that they should create an association for "not-for-profit technicians" who are people that are employed by organizations who often take it upon themselves to be the technical person on staff, even though they have little training or support. These people provide a valuable service to these organizations, basically volunteering their time to do a job that could be a full-time position of its own.

Upkeep and maintenance of a website can also be a full-time job and is often done by these "not-for-profit technicians". The creation, upkeep and maintenance of a website requires a special person on staff with these particular skills. This can create strain for time and resources that could be spent elsewhere. One organization had overcome this problem through partnerships with local industry members who volunteered their time, came in at night and worked on the organization's technology while no one was there. These people are described as a committed group of volunteers who come in and 'play' with the technology to try to come up with the best solutions possible for the organization.

Only one organization actually had a paid webmaster on staff. While this person also engages in project work from time to time, they mainly work on online initiatives and the main focus of their job is to attend to the technology-related needs of the organization. Another organization is currently negotiating with their provincial funder to

obtain money to hire what they call a full-time 'AT (assistive technology) Coordinator'. If the funding comes through, they would be able to hire someone full-time to do website design and maintenance, as well as to help consumers with technology, help students get funded to purchase AT, and work with organizations, libraries, schools, and government departments who are working on issues of access to technology for people with disabilities. This would take away a lot of the unpaid duties currently being done by other staff persons, so that they could focus on the main duties of their jobs. The person I spoke with said that this position could set a standard for other organizations and put pressure on funders to fund these positions by setting an example of the need for them within the organization. It took the organization over 5 years to get to the point where the funders are now considering that the position is needed. They said, "There's a need. Community realizes there's a need, government recognizes there's a need for an AT coordinator, but who's going to fund it? It's thus been unfunded." (interview with representative of disability organization)

The organizations I spoke with were not satisfied with their current web design, overall. Most of them said they would like to have more content available, an upgraded look to the site, increased navigability. Only one organization's representative was moderately satisfied, but even they said that a website has to be constantly evolving, changing and being updated in order to keep it effective. One person described their project's website as an 'intelligent website' because it could remember a person each time they logged on.

> Often, websites and eLearning…can be too static and too dry. With the more two-way conversations… I call them intelligent websites. The person can go, log on, and the website remembers who this person is, it remembers the particular profile, we are even going to

> have it set up so it remembers their personal affirmations, what are their goals, what are their objectives… And it will remind them each time they log on, it will give them a reminder of why they are doing the program… So it's an encouraging website. (interview with representative of disability organization)

They believed that these types of websites are more effective for the online engagement of persons with disabilities because it allows the organization to learn as much from the person as they could ever teach them. For effective engagement, there needs to be a two-way flow of information.

Organizations are also finding that communicating information to their members online, via their websites is proving to be effective. They find it more cost effective than mailing things to their members, and appear to do so now only by request or when the information has yet to be put onto the website. They are also finding that their members are requesting more and different types of online engagement.

> The website is grown to where some people want message boards, again this online environment, streaming video and stuff. So this year, we went out and actually got a media server, so we can provide live streaming media, host this online environment so that people can interact with each other. (interview with representative of disability organization)

It must be noted, however, that as websites have given organizations more effective ways of engaging their communities, it does not come without a cost. As indicated in the quote above, a website can broaden the scope of an organization. Once a community gets a taste of what can be done through technology, the organization begins to grow. One person I talked to said,

> Costs of mailings are down, on the other hand, the more you increase your online capacity, your web-capacity and electronic communication, the greater your capacity to do work. So that you take on bigger projects, your organizational work expands, so all those things increase. Your revenues may increase, but so do your

> costs. The whole capacity of your organization becomes bigger, which is what you want. You want to be able to reach more people in meeting your mandate. But it also increases your capacity, the scope of your organization and can increase your costs...It's a good thing, but you have to make sure that you have the revenue to support what you want to do. (interview with representative of disability organization)

It is important that organizational funding reflect the scope of the work being done by the organization and that it is not simply assumed that technology will make the work possible.

Internet Relay Chat (IRC) and Instant Messaging (IM) Services

For organizations whose membership or board are spread across vast geographic space or have limited mobility, IRC and instant messaging can be effective ways to hold online meetings. Instant messaging is a two-way flow of instant conversation. As the name suggests, it involves two people sending messages to one another and receiving instant responses. Chat is also a form of synchronous conversation and can be done with more than two people. In a closed chat site, organizations could hold virtual meetings where people type in their messages and read the responses as they come up. If you add webcams, you could even see the people you are conversing with. This technology has been the least experimented with by organizations, but can prove quite effective. Accessibility issues need to be considered, but there are many possibilities for this online medium.

One of the representatives I spoke with said that Instant Messaging (IM) has been especially embraced by people from the Deaf community who access technology from their CAP site. They initially had security problems with IM program they were using because people could sign in and out of other people's accounts. However, the users

solved this issue for the organization by going out and researching the technology and they found a web-based instant messaging service, which solved the problem.

One organization did a workshop in a chat room and found they had a very positive response. They said that people were completely different in a chat environment than they were in person. It helped them to shed any inhibitions they might have and participate more fully.

Message Boards and Listservs

A listserv is a mailing list service that people use to communicate en masse via e-mail. People subscribe to a particular group by supplying minimal information about themselves, usually just an e-mail address. E-mail messages are sent to a central e-mail address where they are then sent out to everyone who subscribes to the list. People subscribing to the more popular listservs can get dozens of e-mails per day relating to the topic of the listserv. Bulletin boards operate in similar ways to listservs, except that there is a central website where all previous posts are kept so that the page becomes a repository of information for the group. Rather than having to save hundreds of e-mails sent to your inbox, mailing lists store all of the posts and organize them into themed threads where anyone subscribed to the group can access them at any time. One person said that their Board enjoyed the message board structure, "Everyone loves the idea that you have an archive of material there" (interview with representative of disability organization). These are valuable, interactive tools that organizations can use to get feedback from their members in an open dialogue that has no deadline or end date. They work particularly well for brainstorming sessions, as people can think on their responses and respond in their own time. While extremely effective, the software is not always

accessible to people using screen-readers and organizations often need to alter the software to ensure that their technology meets their accessibility guidelines.

Only two out of the three organizations I studied were making use of message boards and listservs, although one of the representatives of the third organization indicated that there was "a move afoot" toward using them in the future. One of the people I talked to said that they had relatively low response to their message boards and listservs because it serviced a marginalized population and most people would not easily find out about their message boards and listserv. This person thought that even people from within that population want to go to the larger, more popular boards or lists (like Yahoo) because they know they will find more people there.

The other organization is making very effective use of their message boards and listservs. In particular, they have a listserv that is a moderated discussion group which can be set to 'digest mode' which means that you would only get one e-mail from the list per day, rather than many. It is open to anyone interested in the activities of the organization, whether they have a disability or not, and is used in many interesting ways. First of all, the organization uses the listserv to circulate up-to-date information to its members in a way that is much quicker than simply posting the information to the website, which can take more time. One organization runs ideas by their membership through their listserv and can get quick feedback from their members on a variety of organizational topics. They can either present a topic for discussion or sometimes the members do it for them. They can alert their members to upcoming events, new publications, and keep them abreast of the activities of the organization. They also use the

listserv as a way to hear from their members as to the direction they would like the organization to take. For example, one representative of this organization said,

> People raise issues that we, maybe are not addressing as an organization. And from that it helps us develop our organizational work and our priorities in the same way that our national conference does...based on the recommendations we get. (interview with representative of disability organization)

They also said that it posed an opportunity to bring their members and Board together, "That's an opportunity for Board members to interact with the membership on a day-to-day basis on the listserv as well." (interview with representative of disability organization)

Message boards and listservs can be an effective means of support for people with disabilities as well. One person I spoke with said that they were especially effective for online support groups. While not everyone I spoke with agreed with this, some representatives believed it was an effective way to support and empower people with disabilities. For example, it can be a way for people in small, rural communities to feel connected to other people with disabilities in larger cities, "I think [technology] might give [people with disabilities] a better sense of community. If they're in a small town and they know that...they can be in touch with people anywhere, that might not be in their city, but that might be able to help them problem solve." (interview with representative of disability organization)

Many of the people I spoke with said that online communication was an effective way for people with disabilities to overcome social prejudices and biases that are often associated with disabilities. Because of the anonymous nature of the online environment, people with disabilities can choose to disclose the nature of their disability, or in fact

whether they have a disability or not. In essence, they find it to be an environment where they don't need to be defined by their impairment. One representative said that she thinks the people that access their message boards and listserv find it to be a very positive experience.

> I think that it's really a positive thing [online communication groups], and I think that it really supports them as individuals. I think that they feel like there are no biases out there against them. They're just a person. It depends on how they're approaching it and what they're involved in. (interview with representative of disability organization)

Another organization purchased a rather costly piece of software, called Macromedia Breeze that was used to facilitate online course delivery. This particular project was an employment-related project that taught customer service and other employment-related skills. The organization decided that it wanted to offer the course online for people who could not access the project site because of geographic location, in essence widening their target community. However, they initially had concerns about offering courses online. Their biggest concern was that they believed their members would need someone to speak with live if they had questions or needed support. They overcame these concerns by purchasing Macromedia Breeze, which allows them to post lesson modules online, and have online workshops with video linkage, so that the person taking the course knows that there will be a set amount of time each day that they can go online, access the site and have real-time discussion with the course instructor. There is also a 1-800 number they can call for technical support and additional course assistance. The person that devised the course decided that an online version could be a supportive environment, with actual instruction done by people they can see and/or hear live. They told me, "The project sites are so successful because the project staff are right there, in

the program with them 100% of the time, so that if someone is having an issue or having challenges, you have support right there." (interview with representative of disability organization). The program also digitally records the session so that if someone wants to review the video footage, they can. The representative of the organization said that this type of course delivery is beneficial to people who have concerns about traditional class environments to help them overcome their fears.

> A lot of people that have [particular type of impairment] have an overriding anxiety of failure. So if we can get them involved in this program, then through this program they are going to increase self-esteem and self-confidence. That can lead to life-long learning. If we can get them involved with a program that they can actually go online and watch other people in the program do presentations and share their own life experiences, then that's going to give them the confidence that they need to step forward and talk out themselves, and that's a healing process. (interview with representative of disability organization)

The software was also an investment in the organization itself. This program can be used to host online meetings using webcams and microphones and asynchronous chat. This can help organizations consult with their Boards more often than the annual general meeting. The program allows the organization to cast votes, tallies them and keeps the voting confidential. People can make presentations with the program using PowerPoint or by pulling up Word documents to share with the group that can be highlighted and words or phrases circled in the text. The program even takes the minutes of the meeting as it happens. A representative of the organization using this software says that they see it as resource for organizations that need to save costs on face-to-face meetings or to simply keep them in constant communication. The person said, "This is the sort of tool that can really assist smaller, non-profit organizations whether it's by conducting workshops,

online meetings, facilitating training modules…I really see this as helping the disability community as a whole." (interview with representative of disability organization)

The third organization I studied also made use of similar technology, but instead of purchasing expensive software, they invested in the time of their webmaster, who created an online communication vehicle. This vehicle is essentially a closed section of a website that is password protected to ensure that only staff people of the organization and their board members can access the site. The site is then organized as a management tool for the organization, with different sections devoted to different topics that the organization and their board need to discuss. Project members can access sections only devoted to their projects. This tool facilitates online collaboration for the organization and keeps them in constant communication with their board, who manages the operations of the organization while being spread across the country. Applications to funders can be posted for feedback on the site and board members have a chance to review it and communicate their ideas within this online vehicle. If a proposal is made to the organization that they need to review before they can take action, the organization can use it to inform the board members and get feedback and/or approval. Messages have the sender's photographs attached to them and people can use emoticons to express emotion and tone of voice. It is set up and organized like a message board, but it is a truly interactive way for the organization to operate.

The program can take the place of some meetings and conference calls, which they still have, but they can do much more infrequently to save costs. They also do fewer mailings than they did before they set up the site four years ago. The length of time that they have been using online tool is significant as well, as most organizations I spoke with

are only just coming on board with the use of online management tools at the present time. While the most of the organization is happy with the medium some are less enthusiastic. One representative indicated that in regards to the online vehicle

> we are challenged [with our Board] because not everyone likes it…if you ask me how successful it is, on a scale of one to ten, I would say it's about a seven. Because not everyone goes up there. I have a concern about that and I continually voice that. I think it needs to be a combination of [the online organizational tool] and email.

They are also cautious about their level of online organization.

> At the same time [that we are happy about it], we want to be careful. We don't want to become… a virtual organization. We want to continue to be able to mail things to people and to communicate with people using different methods, like a broad-based approach to our communications strategy. (Interview with representative of disability organization)

Another representative from the same organization agreed, "the degree to which we use our internet presence is great, but I'm always concerned about the folks who don't have access and the degree to which we are shutting people out." (interview with representative of disability organization)

One thing that was unique to how this organization works is that time spent on technology for other organizations appears to take away from their other work, whereas with this organization, time spent on technology is facilitating their work. They use the technology to actually do their work. One representative said,

> I think a lot of organizations have, if you visit the offices of a lot of organizations they probably have a lot more technology and a lot more computers and desks and things like that, but our organization….I think we're really innovative in what we do, we've got people across the country, volunteers and consultants…all communicating using different tools. A lot of web-based tools. So I think we've been very innovative in what

we've done. (interview with representative of disability organization)

I found it interesting that a lot of the organizations I spoke with are doing more and more of their work online. This indicates that organizations are moving away from being controlled by the technology, toward harnessing technology to work for their purposes and goals. In this way, their operations become less technology-driven as they take control of technology and make it work for them.

Cost of Technology-Related Activities

With more sophisticated uses of technology come additional costs. Most of the organizations said that technology-related costs were a relatively small part of the overall budget of the organization. This can be explained in many ways. First, most of the organizations said that their core operational funding does not allow for the purchase of technology, although it may allow for some training. Therefore, organizations have had to find creative ways of financing their technology-related needs. This often entails taking on additional work, or projects, that generate revenue for the organization in ways that allow for the purchase of technology. For example, one organization purchased a Braille printer and began contracting themselves out to businesses and other organizations that needed to have their documents in Braille. The small fee charged for this service created enough revenue to upgrade the staff's computers. Other technology-related costs are somewhat "creatively" incorporated into various project funding. Since funding for technology is being raised in a relatively ad-hoc manner and not as part of the organization's overall budget, it may be possible that the organization thinks that their overall costs are lower than they really are or that money that would have been spent on

more traditional forms of communication like the telephone and mail is being saved because of the technology, allowing it to be spent elsewhere. As one person said, "On a day-to-day basis, the cost of electronic communication is relatively inexpensive compared to the cost of bringing people to a meeting from across the country." (interview with representative of disability organization)

Another explanation for the perceived low cost of technology by organizations is that many of the organizations are not accounting for the costs involved with time spent on the maintenance and upkeep of technology as well as new technology development. For example, when I spoke with one person from an organization, they estimated their costs were quite low at roughly $50,000 that year. However, when I spoke with another person from the organization, they estimate that it was closer to $125,000 because of a particular piece of software that was purchased that year as well as some infrastructure costs and staff time devoted to instituting a new project that was considered "technology heavy". The first person I spoke with did not take into account the staff time that was used to develop the program and put it into place. In fact, many organizations are not accounting for time spent on technology when they estimate their overall costs. This may be, in part, due to the fact that a lot of this work is being done by unpaid volunteers or staff members who have incorporated these additional duties into their already full-time jobs.

When asked how much of the organizations' time was spent on technology-related activities, all organizations said that it was a relatively large amount of time. They estimate that as an organization, they spend upwards of eighty hours per week on technology-related activities. That equates to two full-time positions. If organizations

were funded to hire two more people, such as the webmaster that one organization employs or the full-time AT coordinator that another is attempting to make the case for, it would free up their time to allow them to focus their attention more fully on their actual duties and responsibilities within their organization.

5. Implications for Policy

Community development organizations of people with disabilities in Canada are highly involved with many aspects of government policy. Firstly, many organizations are dependent upon government for funding to run their programs. Secondly, many of the activities these organizations undertake involve lobbying government for policy changes and additional program and funding opportunities for the people they work with in their community. Finally, government makes significant decisions regarding the economic, social and political development of the country at all levels. And while the government is an important facet of the organizations' work, the relationship is not always an easy one. Changes in government, including prime ministerial changes, ministerial changes, and staffing at the local level can affect how effectively organizations work with the government.

There is currently little funding available for the technology-related needs of organizations. Writing about the technology needs of the voluntary sector, Sarah Green notes "a general lack of sustained support for the mundane practicalities of introducing computing technologies to the 'socially excluded' was seen by many voluntary sector organizations... as a key difficulty for a whole range of public-sector plans, strategies,

programs and other-named projects in the ICT sector."[138] In April 2004, the Information Highway Applications Branch of the Federal government cut back on Community Access Program (CAP) funding that enabled the general public access to technology they would not normally be able to afford and the trend has moving toward government programs that don't support the technology-related costs of community development organizations using ICTs.[139]

By asking organization about the costs and resources associated with their technology-related activities, this research is able to paint a picture of the strains that technology and technology-related work have put on their organizations. Too often, funders, including government, assume that technology is making their jobs easier, as indicated by one representative who said that their funders have cut back their expenditures for more traditional forms of communication, like mailings. This person said that "[providing more traditional methods of communication] becomes a burden as well because when we go and ask for dollars for funding, governments expect that everyone can access online. So they cut different [budget] lines." It's also important to note that organizations may not be aware of how much time their organization devotes to technology and technology-related activities because a lot of the work is being done by volunteers or incorporated into larger job descriptions. When volunteers are unavailable the burden of this work falls upon staff members who are already overtaxed and uncompensated for much of the technology-related work that they do. If governments and

[138] Green, S. 2003. "Digital Ditches: Working in the Virtual Grassroots," in Garsten and Wulff. 2003. *New Technologies at Work: People, Screens and Social Virtuality.* (New York: Berg), p. 46

[139] Bodnar, C., M. Moll and L. Regan Shade. 2004. *Information and Communications Technology (ICT) Road Map.* (Canadian Research Alliance for Community Innovation and Newtworking: CRACIN). http://www.fis.utoronto.ca/research/iprp/cracin/policy/e-policy_map.html#subhead1B

other funders acknowledged the value to the organization of the work being done, core funding for the organizations would cover these positions as well as other technology-related infrastructure costs.

Secondly, governments need to be aware of how programs like CAP support not just individuals with disabilities, but also organizations. The representatives from the organization that hosts a CAP site spoke to how this program has enabled organizations to purchase technology including computers, printers, fax machines, scanners and other forms of assistive technology that the organization couldn't have otherwise afforded. Interns provided through this program have been so integral to the organization that one even stayed on board as a program coordinator and "not-for-profit technician" two years after the funding ceased. Governments also need to acknowledge the strains on the organizations that these programs create when they are structured in ways that are not sustainable over the long-term. For example, after CAP funding ceases, consumers at the organizations still expect the same level of access, training and support that the program provided. The burden then falls to the organization to keep those sustainable. This adds additional work and financial burdens to the organization that go unrecognized and unsupported by government.

Finally, this research has highlighted those areas in which organizations are struggling in a way that can advise governments at all levels on the types of programs and policies that will assist the organizations doing community development in their work. For example, governments should create programs that are dedicated to the purchase, maintenance and upkeep of technology. Rather than having to incorporate these costs under other budget lines or raise revenues from their own creative sources, funding for

these types of expenditures would add resources that traditionally would have gone to other programs and services for people with disabilities. It would also make the organizations more aware of the technology-related costs that may go unaccounted for within their organizations. Finally, governments should supply funding for organizations to hire full-time AT Coordinators, like the one described in the section above called "Cost of Technology-Related Activities". The research conducted for this thesis has illustrated a need for these positions within community development organizations of people with disabilities. The functions of this position are currently being carried out on a largely volunteer basis by people who are required to take time from the duties and responsibilities of their actual positions. This means that while the work has value to the organization, it is still taking away from other important duties and responsibilities that the organization must fulfill as part of its mandate. It is key that organizations be supported financially in ways that will free 'not-for-profit' technicians to do the jobs that the organizations have hire them to do.

What this project hopes to bring to the table is information regarding the ICTs needs and desires of organizations working with people with disabilities. By compiling information about what organizations have experienced and what they have found lacking, this thesis should serve as a document that can be taken to government to show exactly what government can do to make the work of these organizations.

6. Implications for Theory

As discussed in the literature review portion of this thesis, the various conceptual models that have influenced our understanding of disability at different points in time have also influenced the way that organizations of and individuals with disabilities

approach the use of information and communications technologies. How technological innovation is approached by organizations, the success with which it is met by consumers, and the level of sophistication employed all relate to our understanding of the role of the disabled in the social, political and economic realms. In particular, conceptual models have a role to play in whether organizations determine the social uses of the technologies they employ or are, in turn, driven by the determinant forces of technology. The following section will elaborate on the use of conceptual models, in particular the ways in which an organization's principles affect their use of technology, the social shaping of technology by organizations of people with disabilities, and how the organizations understanding of community and development affect their uses of ICTs.

Most public access to technology provided by governments is rooted in the *charity* and *medical models* which view disability as "a consequence of some tragedy, requiring a human response, most commonly of sympathy or charity," or requiring the intervention of professionals in order to overcome physical and/or mental limitations.[140] People with disabilities are viewed as one of the many minority groups mired in the so-called 'digital divide.'[141] One of the most common responses to the digital divide have been to provide public access to technology, by funding the purchase of computers, printers and internet connections and placing them within public libraries and community organizations, such as the ones studied in this project. Public access to technology is philanthropic in approach, because while these programs are instituted with good intentions, they are rarely backed up with sufficient resources to make them sustainable. In this way, programs like the Community Access Program (CAP) create a demand for

[140] Enns and Neufeldt 2003, p.4
[141] Servon 2002

the services, training and access they provide and make communities dependent upon their funding in order to keep them sustainable. One of the organizations interviewed in this project spoke to the demand that the program created and said that their consumers insisted upon keeping the site running even after CAP funding concluded. This particular organization was in a position to do so, but many others are left with few resources or support to be able to continue, leaving the consumers who became dependent upon that access disappointed and without access once again. Philanthropic models of access provision are rarely sustainable, for they are dependent upon financial resources and other forms of support that are not guaranteed for the long-term.

However, approaching public access to technology in a way that is based upon the social model of disability rectifies many of the problems associated with charity and medical model approaches. One of the organizations provided access to technology and had received CAP funding in the past, but because of the principles upon which the organization operated, they have had more success with their program than most. For example, this organization believes in consumer control, choice, and the freedom to take risks and make mistakes. These principles, according to Barnes, are rooted in the social model.[142] They have driven the organization in the public provision of technology. The organization provides a variety of hardware and software choices for the consumer to try out and then they decide which type of technology works best for them. In this sense, the consumer is the one in control of the process. The organization also set up workshops that teach consumers how to build and maintain their own computers, host a repository of spare parts that they can access to build or repair their systems and has someone on had

[142] Barnes, C. 1998. "The Social Model of Disability: A Sociological Phenomenon Ignored by Sociologists?" in T. Shakespeare. 1998. *The Disability Reader: Social Science Perspectives*. (London: Continuum), p. 65-78

for support. This creates the type of access that is sustainable over the long-run, because they consumer has choice and control of the process. The organization is also unique in that they provide funding for transportation to and from the organization for consumers to access their computers. This funding is not provided for through the CAP program, but was an important part of creating access for people who would not have afforded the transportation required for using the facilities. Attention to this kind of detail is a result of the acknowledgement that people with disabilities are not accommodated in the social, political and economic realms and may require additional accommodation to overcome this lack of accessibility, an approach rooted in the social model.

In contrast, the medical model of disability influences an approach to technology that views a person with a disability as a person that needs to be fixed and for whom technology can be an appropriate intervention in that process. In this way, technology is approached as a way to fix or cure the 'problem'. Benefits are provided through government programs that help people buy computers, software, and other assistive devices, usually through social welfare programs, but the process is very prescriptive and the individual is often told which type of technology or software would work best for them. They usually have very little control of what is purchased for them or how it is to be used. This approach is deeply rooted in the medical model and does not work well for the individual.

Aside from public access to technology, conceptual models can help us to understand the ways in which organizations use technology in their efforts at community development, to work within their organizational structure, and in relation to their communities. As stated earlier in this thesis, a move toward the social model of disability

has led to the increased politicization of the category of disability and of the activities of the organizations that form the disability community. This has led to organizations that are much more involved with social change and radical democracy than the organizations that predated them. Like many social movements, the organizations that are involved with the disability rights movement have begun to embrace ICTs in their work. They have approached the use of technology in a much more cautious way than other groups, however, because of their experiences with inaccessible environments, technology that has been created without accessibility in mind, and other barriers that they have had to overcome. All of the organizations that I spoke with were keenly aware that people with disabilities have unique issues and concerns that may create barriers to their accessing technology and have all dealt with these issues in their own way.

To simply state that ICTs do not work for engaging people with disabilities would be to submit to technology's deterministic tendencies. By this I refer to the earlier discussion in the portion of the literature review that discussed Community Informatics. CI avoids overly technical approaches to ICTs, much in the same way that many organizations of people with disabilities have approached their uses of technology. Overly technical approaches to technology view ICTs as a determining force for social change which gives little space for human choice. This approach is reminiscent of the medical model because people with disabilities, due to the nature of their impairments, lack the ability to determine the way that technology affects their lives. The fear is that technology is infused with the same inherent biases as the social, political and economic realms from which people with disabilities have been systematically excluded. If technology is embedded with these same biases, then technology is part of the systemic

oppression of people with disabilities. However, an approach that is born out of the social model would accept that by embracing technology for their own purposes, organizations at the mature stage of technological sophistication have taken the so-called 'driver's seat' in their use of ICTs. They don't allow technology to drive the agenda, nor do they believe that there is anything inherent in technology that cannot be subsumed to their own purposes. Just as the social model emphasizes the need to change the social and built environments to be more accommodating of the needs of people with disabilities, so this approach sees technology as something that can be molded to their own purposes. They simply use technology as a tool to create their own agendas and to facilitate their goals.

The literature refers to this as the 'social shaping of technology', which means that the technology is of secondary importance to the social, political, economic and cultural objectives of the project.[143] This is what makes the organizations at the *mature* stage of technological sophistication unique from those at the other levels. While organizations at the *emerging and expanding* stage of technological sophistication are using technology in very positive ways, they have not yet fully embraced the potential of ICTs, for various reasons. The organizations I spoke with, who were in this stage of development, had not fully embraced technology because it was still a very contentious issue within their organizational structure. There were still those people within the organization who were very cautious about broadening their approach to the use of ICTs, mainly for fear that they would be leaving people out. Ironically, these organizations often offer public access to technology and have noted that their consumers are excited about technology and seem to be fully embracing its uses.

[143] Keeble and Loader 2004

Another reason for their cautious approach to technology connects with an interesting discussion in the literature. Writing within the field of Human Geography, Gleeson has said that "space is a social artifact that is shaped by the interplay of structures, institutions and people in real historical settings."[144] If this holds true, then organizations of people with disabilities can create their own spaces using technology to overcome the biases inherent in society. However, not all of the organizations I spoke with felt this way. One representative said that they had concerns about the use of ICTs as a mode of communication with people who are in the midst of difficult situations and stressed the importance of face-to-face contact. This person stressed that technology is not capable of creating the space for human interaction because there is a 'falseness' to technology. I believe that what this person was referring to was the same theme which I picked up on in the literature that discussed 'authentic' vs. 'inauthentic' places. Relph (1976) was on of the first geographers to examine the notion of 'inauthentic' places and ignited a dialogue that now includes Baudrillard (1983), Rheingold (1993), Jess and Massey (1995), Dodge and Kitchin (2001) and others. These authors are all interested in how online interaction can create an antidote to the 'placelessness' that is attributed to modern society and the subsequent loss of community caused by a weakening of the identity of places (see section 2.5.2 Place/Placelessness in the literature review portion of this thesis). I believe that the person I interviewed did not believe in the potential of online interaction to create authentic spaces for human interaction.

Many organizations are moving toward the use of ICTs to overcome the loss of community described by the abovementioned authors. In the literature review portion of the thesis that discussed the conception of community employed in Community

[144] Gleeson, 1999, p. 2

Informatics, I described a debate that analyzed the loss of community in modern societies and its relation to technology. I wrote that some analysts describe this loss of community as resulting from the increasing use of ICTs, while others say that online interaction can provide an antidote to the loss of community by empowering communities to network with one another (see section 2.3.1 Definition of Community). I believe this relates to the social shaping of technology and the deterministic forces of technology described earlier. If organizations believe that there is something inherent in technology that leads to social disintegration, they will not embrace the use of ICTs. However, organizations that believe that they can shape the social effects of technology will embrace the use of ICTs for their own social aims. In this sense, organizations have found exciting new uses for ICTs that lead to community engagement.

It is important to note that the way in which an organization defines community is an important part of this process. If organizations define community based upon shared interests and common goals rather than geographic location, they are more likely to embrace the use of online interaction to create new public spaces for interaction and engagement. Dodge and Kitchin explain, "...individualistic, like-minded people join forces to form public-based communities; cyberspace offers the opportunity to reclaim public space and recreate online, the essence and nature of authentic places which are disappearing from geographic space." This is why I believe that the field of Community Development has not come on board with the use of ICTs, because their definition of community is rooted in geographic space. From their standpoint, authentic spaces cannot be created online, because community involves a geographic anchor and technology leads to a dislocation of community in geographic space.

However the form of community development pursued by the organizations in this study is conducive to the social shaping of technology. These organizations use technology to network with one another, work across vast geographic space, and to engage the members of their communities for political action and social change. Because their mode of community development involves mainly capacity building exercises, ICTs can be shaped to meet the needs of their target populations.

As Shirlow and Murtagh define it, capacity building is a form of social capital development that aims to "activate localized social networks in order to mitigate the impact of social exclusion."[145] As discussed in section 4.3.1 of the Research Findings, the organizations of the disability community focus on three areas of capacity building: employment, political engagement and community awareness programs. Organizations are able to shape technology, in particular ICTs, to meet these goals in significant ways.

First, organizations provide employment opportunities and training to their members by online course delivery, online employment sites that connect people with disabilities with potential employers and by employing people with disabilities across vast distances through home-based employment and contract work. Organizations at the *emerging and expanding* stage of technological sophistication have focused upon employment training and some online course delivery, but have not engaged with their members to the degree that those at the *mature* stage have. For example, they employ people with disabilities within their offices, but have serious reservations about home-based work. Their reasons for this are more than valid, but organizations at the *mature* stage have been able to move past their reservations and to address their issues and concerns in ways that are conducive to all involved. For example, they hire people to

[145] Shirlow and Murtagh 2004, p. 57

work for their organization based upon their skills and abilities, even if they cannot work within the office setting. They do so by ensuring that it is the individual's choice to work at home, by facilitating face-to-face meetings so that the individual is not working in complete isolation from the rest of the staff and by making sure that the technology that is used to facilitate the process works for everyone involved. The organizations employ online organizational tools, but insist that people maintain more traditional modes of communication, such as telephone or mail, when appropriate. The organizations at the *emerging and expanding* stages have simply not yet found ways of making technology work for them. They need to believe that the use of ICTs for this type of employment will not further isolate individuals or exacerbate the oppression which they already face. It is not to say that these organizations cannot use ICTs as effectively as those at the *mature* stage, they have simply not found the most appropriate way to make technology work for them.

Secondly, organizations are using ICTs to engage their members in the political goals of the organization. Those at the *emerging and expanding* stage of technological sophistication are doing so mainly by providing their members with information and communicating with them through ICTs. This approach is meeting the needs of the organization in that it saves time and money in comparison to more traditional methods, but is not unique to the approach to capacity building used in the past. Providing one's members with information they need to make informed decisions is a valuable part of capacity building and is viewed as a civil right by organizations of people with disabilities. Communicating upcoming events to their members and to other organizations is an important part of political organizing that mobilizes people to social

change. However, organizations at the *mature* stage of technological sophistication are using ICTs in unique and innovative ways to engage their members. They are consulting their members through message boards and list-serves and allowing them to drive the organization's political agenda in ways that are much more interactive than more traditional forms of communication and information provision could ever be. While organizations at the *emerging and expanding* stage are using technology to do the same job in different ways, those at the *mature* stage are using technology to change the job they are doing. Political engagement at the *mature* stage involves a much more interactive form of engagement with their membership. Rather than simply providing information and communicating with their members in a one-to-one, asynchronous manner, organizations at the *mature* stage are using synchronous many-to-many modes of communication to have a dialogue with their membership about their political goals and strategies. This involves the membership in the workings of the organization in a much more complex and innovative way. It also keeps the organization more accountable to their membership. Activities involved can include brainstorming, problem-solving, online voting, strategizing, and planning. These organizations are including their members in ways that they previously have never done. In addition to this, organizations at the *mature* stage are continually looking for new and innovative ways to engage their members.

Finally, organizations are using technology in community awareness building activities that aim to educate the broader public about the work of their organizations and the issues unique to people with disabilities. Organizations at the *mature* stage of technological sophistication are using technology to engage with communities outside of

their traditional focus in order to pursue the goals of the organization. Every organization I spoke with talked about how technology was broadening the mandate of their organizations and making them more national in scope. Those at the *emerging and expanding* stages even spoke about working with other disability organizations from around the world because of the ways in which technology has increased their ability to network. However, only those at the *mature* stage spoke to the ways in which technology has enabled them to engage with organizations outside of the disability community. They worked with people with similar interests but diverse backgrounds. They participated in list-serves and interjected their viewpoints on the message boards of groups outside their traditional community, making them more aware of the concerns of their members and building a broader base of support for their goals.

Further research is needed to track the progress of organizations along the continuum of technological sophistication. It would be an interesting facet of this research to track the progress of the organizations studied over time in order to determine if they are evolving along the continuum or remaining within their stage of technological sophistication. It is my guess that they will continue to evolve and develop along the continuum as they see other organizations making progressive use of ICTs. It is my belief that over time, organizations of people with disabilities will see that they can shape the social uses of technology toward their own aims and goals and that people with disabilities do not need to fear technology, they need to control it and put it to their own purposes.

7. Conclusion

Organizations of people with disabilities in Canada are generally hesitant in their use of ICTs and for good reason. Historically, people with disabilities have been an oppressed minority, subject to social prejudice and systemic exclusion. Arising from a history of over-medicalization, people with disabilities have been wary of 'experts' who tell them about how they should live their lives. Technological innovation requires the role of an 'expert' to explain how technology works, its purposes and potential uses. People with disabilities have been told what works for them for too long. However, technology, and the 'experts' that introduce technology to organizations of people with disabilities, do not have to determine the course that we take with technology. Organizations of people with disabilities can shape technology to suit their needs and purposes and those of their members. As people with disabilities we shape our own futures and our own experiences with technology.

When I began this research, I had very clear objectives and goals about what I wanted to learn. The organizations that formed the basis for the case studies have gone far beyond my expectations in providing me with the information to meet those goals. By asking organizations about their needs and experiences, I have learned more about how organizations function, their creative potential and the differences that they make not just in the lives of people with disabilities, but also in the social, political and economic realms in which we all live and function. These organizations make valuable contributions that strengthen the very foundation of our society.

The shift toward a knowledge-based economy has had a very real effect on how the organizations in the disability community structure their work and how they perceive their role in the voluntary sector. In fact, while much of the work itself remains the same,

the ways that organizations facilitate their work have shifted. The shift toward a knowledge-based economy may be highly beneficial to organizations of people with disabilities because the importance of ICTs has presented them with an opportunity to shape technology and their experiences within the knowledge-based economy to work for them in the achievement of their goals. It is clear to me that ICTs can be beneficial in helping organizations survive the shift toward a knowledge-based economy, they simply need to harness its potential.

References

Barnes, C. 1998. "The Social Model of Disability: A Sociological Phenomenon Ignored by Sociologists?" in T. Shakespeare. 1998. *The Disability Reader: Social Science Perspectives*. (London: Continuum), p. 65-78

Barton, L. and C. Barnes (eds). 1997. *Disability Studies: Past, Present and Future.* (Leeds: The Disability Press)

Baudrillard, J. 1983. *Simulcra and Simulations*. (New York: Semiotext(e))

Beckstead, D. and T. Vinodrai. 2003. "Dimensions of Occupational Changes in Canada's Knowledge Economy, 1971-1996," *The Canadian Economy in Transition Series*, No.4. (Ottawa: Industry Canada)

Bodnar, C., M. Moll and L. Regan Shade. 2004. *Information and Communications Technology (ICT) Road Map.* (Canadian Research Alliance for Community Innovation and Newtworking: CRACIN). http://www.fis.utoronto.ca/research/iprp/cracin/policy/e-policy_map.html#subhead1B

Cameron, D. and F. Valentine. 2001. "Comparing Policy-Making in Federal Systems: The Case of Disability Policy and Programs- An Introduction," in D. Cameron and F. Valentine. 2001. *Disability and Federalism: Comparing Different Approaches to Full Participation*. (Montreal & Kingston: McGill-Queen's University Press)

Campbell, J. and M. Oliver. 1996. *Disability Politics: Understanding Our Past, Changing Our Future*. (London: Routledge)

Canadian Centre on Disability Studies. 2002. *Best Practices in the Home-Based Employment of People with Disabilities*. (Winnipeg: CCDS)

Castells, M. 1988. *The Information City: Information Technology, Economic Restructuring, and the Urban-Regional Process*. (Oxford: Blackwell)

Chouinard, V. 1997. "Making Space for Disabling Differences: Challenging Ableist Geographies," *Environment and Planning D: Society and Space*, 15, 4, p. 379-387

Cohen, R. and S.M. Rai. Eds. 2000. *Global Social Movements*. (London: Athlone Press)

The Daily. 2002. "Information and Communications Technologies (ICT)," (Ottawa: Statistics Canada) available online: http://www.statcan.ca/english/freepub/13-605-XIE/2003001/classification/ict/2002note.htm

Davison, E. and S.R. Cotton. 2003. "Connection Discrepancies: Unmasking Further Layers of the Digital Divide," *First Monday*, 8, 3, Available online: http://www.firstmonday.org/issues/issue8_3/Davison.html

Delanty, G. 2003. *Community*. (London: Routledge)

Dodge, M. and R. Kitchin. 2001. *Mapping Cyberspace*. (London: Routledge)

Doe, T. and Whyte J. 1995. *Participatory action research*. Paper presented at National Institute of Disability and Rehabilitation Research Conference on PAR, Washington, DC.

Downing, R. 2004. "The Role of the Social Economy in Strengthening New Media Development in Canada," (The Canadian Community Economic Development Network) available online: http://www.ccednet-rcdec.ca/en/docs/pubs/FINAL_RoleofSocialEconomyinNewMedia.pdf

Edwards, J. 1997. "Urban Policy: The Victory of form over substance," *Urban Studies*, 34, p. 825-43

Enns, H. and A. Neufeldt. 2003. *In Pursuit of Equal Participation: Canada and Disability at Home and Abroad*. (Concord: Captus Press)

Erevelles, N. 2001. "In Search of the Disabled Subject," in J. Wilson and C. Lewiecki-Wilson. Eds. 2001. *Embodied Rhetorics: Disability in Language and Culture*. (Carbondale: Illinois Press), p. 92-111

Farrington, C. and E. Pine 1992. "Community Memory: A Case Study in Community Communication," in P. Agre and D. Schuler. Eds. *Reinventing Technology, Rediscovering Community: Critical Explorations of Computing as a Social Practice*. (Norwood: Ablex Publishing)

Flatt, J. and B. Pape. 2003. "Stronger Together: Steps Toward a National Mental Health Network," in D. Stienstra and A. Wight-Felske. 2003. *Making Equality: History of Advocacy and Persons with Disabilities in Canada*. (Concord: Captus Press)

Garsten, C. and H Wulff. 2003. *New Technologies at Work: People, Screens and Virtuality*. (Oxford: Berg)

Germon, P. 1998. "Activists and Academics: Part of the Same or a World Apart," in T. Shakespeare. Ed. 1998. *The Disability Reader: Social Science Perspectives*. (London: Continuum)

Gleeson, B. 1999. *Geographies of Disability*. (London: Routledge)

_____1996. "A geography for disabled people?" *Transactions of the Institute of British Geographers*, 21, p. 387-396

Goodley, D. and M. Moore. 2000. "Doing Disability Research: Activist Lives and the Academy," *Disability & Society*, 15, 6, p. 861-82

Green, S. 2003. "Digital Ditches: Working in the Virtual Grassroots," in Garsten and Wulff. 2003. *New Technologies at Work: People, Screens and Social Virtuality*. (New York: Berg)

Gurstein, M. 1999. "Community Informatics," (St. Petersburg: Centre of Community Networking and Information Policy Studies) available online: http://www.communities.org.ru

Hansen, N. 2002. "On Approval: The Geography of Disabled Women and Work," Paper given at the *New Directions in Disability* seminar series, Centre for Disability Studies, University of Leeds, Leeds, April 10th, 2002

Haraway, D. 1991. *Simians, Cyborgs and Women*. (London: Free Association Press)

Harding, S. 1986. *The Science Question in Feminism*. (Ithaca: Cornell University Press)

Hauben, J.R. 1995. "A Brief History of Cleveland Free-Net," *The Amateur Computerist*, 7, 1, available online: http://www.prometheusonline.de/heureka/kommunikationswissenschaft/monografien/hauben/brief.htm

Human Resources and Social Development Canada. 2001. *The Strategic Plan of the Office for Disability Issues, 2002-2007*. (Ottawa: Government of Canada)

Huws, U. 2003. *The Making of a Cybertariat: Virtual Work in a Real World*. (New York: Monthly Review Press)

Jess, P. and D. Massey. 1995. "The Conceptualisation of Place," in Massey and Jess. Eds. *A Place in this World? Places, Cultures, and Globalization*. (Oxford: Oxford University Press)

Kavanaugh, A.L., A.M. Cohill and S. Patterson. 2000. *Use and Impact of Community Networking in Blacksburg*. (Blacksburg: Blacksburg Electronic Village Hall)

Kraut, R., M. Patterson, V. Lundmark, S. Kiesler, T. Mukopadhhyay and W. Scherlis. 1998. "Internet Paradox: A Social Technology that Reduces Social Involvement and Psychological Well Being?" *American Psychologist*, September, p. 1017-31

Kubicek, H. and R. Wagner. 2002. "Community Networks in a Generational Perspective: The Change of an Electronic Medium Within Three Generations," *Information, Communication, &Society, 5, 3, p. 291-319*

Keeble, L. and B.D. Loader. 2004. *Challenging the Digital Divide? A Literature Review of Community Informatics Initiatives*. (York, North Yorkshire: The Joseph Rowntree Foundation), p. 4

Leverus. 2004. *Leverus Annual Internet Survey for Associations and Not-for-Profit Organizations, 2004*. (www.leverus.com)

Linton, S. 1998. *Claiming Disability*. (New York: New York University Press)

Litvak, S., L. Frieden, T. Doe and C. Dresden. 1995. "Empowerment, independent living research and participatory action research," Paper presented at the National Institute of Disability and Rehabilitation Research Conference on Participatory Action Research, Washington, D.C.

MacDonald, L. 2003. "Gender and Canadian Trade Policy: Women's Strategies for Access and Transformation," in C. Sjolander, H.A. Smith and D. Stienstra. Eds. 2003. *Feminist Perspectives on Canadian Foreign Policy*. (Don Mills: Oxford University Press)

Marx, K. and F. Engels. 1848. *The Communist Manifesto*. (Berlin: The Communist League)

Melucci, A. 1989, *Nomads of the Present: Social Movements and Individual Needs in Contemporary Society*. (Philadelphia: Temple University Press)

Metzl, J.F. 1996. "Information Technology and Human Rights," *Human Rights Quarterly*, 18, 4, p. 705-46

Morley, D. and Robins, K. 1995. *Spaces of Identity: Global Media, Electronic Landscapes and Cultural Boundaries*. (London: Routledge)

Naples, N.A. and M. Desai. Eds. 2002. *Women's Activism and Globalization*: *Linking Local Struggles and Transnational Politics*. (New York: Routledge)

Nua, 2002, http://www.nua.ie/surveys/how_many_online/index.html

Oliver, M. 1990a. "Individual and Social Models of Disability," paper presented at the Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on People with Established Locomotor Disabilities in Hospitals.

_____1990b. *The Politics of Disablement*. (London: MacMillan Press)

_____and C. Barnes. 1996. "Discrimination, Disability, and Welfare: From Needs to Rights," in J. Swain, V. Finkelstein, et al. eds. *Disabling Barriers-Endabling* Environments. (London: Sage)

_____and G. Zarb. 1997. "The Politics of Disability: A New Approach," in L. Barton and C. Barnes (eds). 1997. *Disability Studies: Past, Present and Future*. (Leeds: The Disability Press)

Qvortrup, L. ed. 1987. *Social Experiments with IT and the Challenge of Innovation.* (New York: Kluwer Academic Publishers)

PAT 15. 2000. *Closing the Digital Divide: Information and Communication Technologies in Deprived Areas: A Report by Policy Action Team 15.* (London: DTI)

Plant, R., H. Lesser and P. Taylor-Gooby. 1980. *Political Philosophy and Social Welfare.* (London: Routledge & Kegan Paul)

Pitkin, B. 2001. "Community Informatics: Hope or Hype?" *Proceedings of the 34th Hawaii International Conference on System Sciences.*

Poster, M. 1995. *The Second Media Age.* (Oxford: Polity)

Putnam, R. 2000. *Bowling Alone: The Collapse and Revival of American Community.* (New York: Simon & Schuster)

Relph, E. 1976. *Place and Placelessness.* (London: Pion)

Rheingold, H. 1993. *The Virtual Community: Homesteading on the Electronic Frontier.* (New York: Addison-Wesley)

Rubenstein, J. 1999. *The Cultural Landscape: An Introduction to Human Geography.* 6th. ed. (Upper Saddle River: Prentice-Hall)

Schuler, D. 1996. *The New Community Networks: Wired for Change.* (Reading: Addison-Wesley)

Shakespeare, T. Ed. 1998. *The Disability Reader: Social Science Perspectives.* (London: Continuum)

Shearman, C. 1999. *Local Connections: Making the Net Work for Neighborhood Renewal.* (London: Communities On Line)

Shirlow, P. and B. Murtagh. 2004. "Capacity-Building, Representation and Intracommunity Conflict," *Urban Studies*, 41, 1, p. 57

Shragge, E. 1993. *Community Economic Development: In Search of Empowerment.* (Montreal: Black Rose Books)

Simon, W.H. 2001. *The Community Economic Development Movement: Law, Business & Social Policy.* (London: Duke University Press)

Sjolander, C., H.A. Smith and D. Stienstra. Eds. 2003. *Feminist Perspectives on Canadian Foreign Policy.* (Don Mills: Oxford University Press)

Social Development Canada. 2004. *Advancing the Inclusion of Persons with Disabilities.* (Ottawa: Government of Canada)

Stienstra, D. and A. Wight-Felske. 2003. *Making Equality: History of Advocacy and Persons with Disabilities in Canada.* (Concord: Captus Press)

Stringer, E.T. 1999. *Action Research.* 2nd Edition. (London: Sage Publications)

Vaillancourt, C. 2003. "Employment in the Computer and Telecommunications Industries," *Innovation Analysis Bulletin*, 5, 2

VanSant, J. 2000. "Assessing the Capacity of Development Organizations," (Durham: Duke University Press) available online: http://www.ngomanager.org/dcd/2_Organisational_Development/Organisational_Assessment/

Wendell, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability.* (New York: Routledge)

Whyte, W. Ed. 1991. *Participatory Action Research.* (Newbury Park: Sage Publications)

Wilson, J. and C. Lewiecki-Wilson. Eds. 2001. *Embodied Rhetorics: Disability in Language and Culture.* (Carbondale: Illinois Press)

Wood, A.F. and M.J. Smith. 2001. *Online Communication: Linking Technology, Identity & Culture.* (Mahwah: Lawrence Erlbaum Associates, Publishers)

Appendix 1- Glossary

Capacity Building- activities aimed at increasing the ability and skills of individuals, groups and organizations, to plan, undertake and manage initiatives

Community Development- a form of community building that addresses both social and economic need within the target community

Community- a collection of individuals who come together on the basis of shared interests rather than on location or geographic space, characterized by personal intimacy, moral commitment, and social cohesion

Community Development Organizations- groups with a mandate to develop and provide for the social and economic needs of a group of individuals who come together on the basis of shared interests rather than on location or geographic space, characterized by personal intimacy, moral commitment and social cohesion

Empowerment- a process that occurs both at a personal and political level and involves changing power relations between individuals and groups and social institutions

Information and Communication Technologies (ICTS)- technologies used to handle the creation and dissemination of information, such as computers and modems, fax machines, internet and intranets, telephones, the World Wide Web, and various mobile technologies

Appendix 2- Research Instruments

Interview Questions for Lindsey Troschuk's Thesis Research

Staff Members of Case Study Organizations

Introduction

Our economy has been changing rapidly since the 1970s. The main effect of this change is that knowledge and information have become valuable resources that people need to have to compete in the job market. Human capital, skills, innovation and technology are necessary to be competitive. In the 'new economy', there is an ever-increasing demand for a well-educated and skilled work force in all parts of the economy. Your organization was chosen as a case study for this research project because you have been working toward changing the way that the economy affects people with disabilities in your community. This project hopes to understand how the growing importance of Information and Communications Technologies (ICTs), defined as technologies used to handle the creation and dissemination of information, affects the daily operation of your organization and your perceived role in social, political and economic organization in Canada.

SECTION 1- General Overview and Day-to-Day Operations

This section is intended to gather information about the effectiveness and efficiency of the use of ICTs in the day-to-day operation of your organization?

1. What is the official mandate of your organization?

2. Does your organization aim to develop and provide for the social and economic needs of people with disabilities?

3. What are the principles that guide the operation of your organization?

4. How does your organization define its membership (geographically-based, interest-based, etc)? Is your membership defined in the same way that you would define your target community? If not, how would your organization define community?

5. Does your organization identify as part of a larger community or social movement? If so, which one?

6. Changes in government, levels of funding, changes in society and the economy can all have a profound impact upon organizations attempting to impact the social, economic and political needs of people with disabilities. How have these changes affected the role of your organization?

7. Have you noticed other changes in the daily operation of your organization since you have been involved? If so, please describe.

8. Does the organizational memory of the organization, the records and accounts that document the history of the organization, indicate significant changes in the daily operation of the organization? If so, do you think they have made operations more efficient or not?

9. Which ICTs does your organization make use of in day-to-day operations (for example: e-mail, telephone, fax, etc)? Which ICTs are used rarely or for special purposes? Please describe those situations.

10. How do you feel that the use of Information and Communication Technologies (ICTs) has effected the daily operation of your organization? Has it made your job easier or added additional barriers to overcome?

11. Has technology made it easier to employ people with disabilities as staffpersons within your organization? If yes, how so? If no, has it made it more difficult? If yes, elaborate.

12. Do you think that ICTs are effective as a means of communicating with people with disabilities (by fax, e-mail, telephone etc)? If not, what makes them ineffective? If so, do you think they are effective for engaging people with disabilities in the activities and goals of the organization?

13. Please describe the accessibility standards the organization strives to achieve in relation to ICTs. (ie: Website accessibility, TTY number, multiple formats of organization documents, etc)

14. How well has the organization been able to meet these standards? Are there any particular accessibility goals that have been difficult to meet?

SECTION 2- Time and Resources

This section is intended to paint a picture of the amount of time and resources expended by the organization on technology-related issues.

1. When was your organization's website created?

2. Was the site initially created by someone from within the organization? If not, was someone hired from outside of the organization?

3. Is maintenance and upkeep of the site done by someone on staff? If so, is this their sole responsibility or par of a larger job description?

4. Is the organization satisfied with your current web design? If so, did it take a while to get to a state you were satisfied with? If not, what are the issues that concern you (for example: accessibility, navigability, content, etc)?

5. What is your organization's current operating budget? Of that amount, is there an amount set aside for technology-related costs (including training, upkeep, maintenance)? If so, what is the organization's budget for technology-related expenses? If not, where does money for technology-related expenses come from (for example, from other budget items)?

6. How much do you think your organization spends on technology-related expenses per year?

7. Is there money set aside for technology-related accommodations for staff members?

8. How many hours per week does your entire organization dedicate to the development, maintenance and upkeep of web-related activities (for example, on the website or on listservs, etc)?

SECTION 3- Experiences with Government

The intent of this section is to better understand whether or not government is supporting the technology-related needs of organizations working with people with disabilities?

1. Does your organization receive government funding? If so, from what level of government (local, provincial/territorial, federal) do you receive funding? If not, where does the organization receive its funding?

2. If you answered yes to the above question, does your funding allow for budget expenditures for purchasing technology, technology-related services, or to pay for technology-related staff training?

3. Are you aware of government funded programs dedicated to the purchase of technology, technology-related services or technology-related training? If so, please indicate which one(s)?

4. Does your organization host a government-sponsored Community Access Program (CAP) site? If yes, has this been a positive or negative experience for your organization? If it has been a positive experience, please describe why. If it has been a negative experience overall, please explain why.

5. Do you think that CAP sites have been positive for people with disabilities more generally? Why or why not?

6. Does your organization ever engage in lobbying activities, such as letter-writing or election campaigns, research that is aimed at government policy, or broader social goals? If so, can you give some examples of issues for which you have lobbied?

SECTION 4- Technology- Related Experiences of People with Disabilities

This section is intended to obtain your opinion on the overall impact of the use of ICTs on the lives of people with disabilities.

1. Do the people who communicate with your organization via the Internet (by e-mail, on listservs or message boards) identify the nature of their disability or disabilities online?

2. Do the people who communicate with your organization via the Internet identify themselves as members of a broader social movement? To your knowledge, do they ever engage in lobbying activities, such as letter-writing or election campaigns, research that is aimed at government policy, or broader social goals?

3. Do the people who communicate with your organization via the Internet discuss their impairment(s) or the effects their impairment(s) have on their ability to function in society?

4. Do you that the participation of people with disabilities in online environments impacts upon their identity? If so, how? If not, why do you feel it has no effect?

5. Does your organization have a policy to ensure the privacy of information provided by people with disabilities online? If so, how do you ensure the privacy of people online? If not, is this something you think would be possible or necessary?

6. Does your organization have a policy to ensure that people with disabilities are accurately representing themselves online (for example, claiming to have a disability when they do not)? Do you think this is an issue of concern to people with disabilities?

7. Do you think that technology, and the Internet more specifically, is of benefit for people with disabilities or does it create more barriers to the participation of people with disabilities in social, economic and political life? Please explain your answer in detail.

8. What do you think are the most important issues to consider when attempting to engage people with disabilities online? Please provide as detailed answers as possible.

Intake Form for Demographic Information for Case Study Organizations

Name:

Organization:

Position in Organization:

Please give a short description of what your job entails in the space below:

How long have you been in your current position?

Have you ever held any other positions in the organization? _____yes _____no

If yes, please describe any other positions you have held at the organization in the space below.

What types of internet connections are available in your area?

Broadband____ Dial-Up_____ High-Speed_____

Light-Speed_____

Which, if any, do you prefer?

Broadband____ Dial-Up____ High-Speed_____

Light-Speed_____ No Preference_____

Which type does your organization use?

Broadband____ Dial-Up_____ High-Speed_____

Light-Speed_____

Please indicate, in the space below, the reasons for the selection of the type of internet connection your organization uses (for example: cost, speed, efficiency, preference)?