

**ON BECOMING A DIRECTOR: CONSTRUCTING VOICE  
FROM WITHIN A MARGINALIZED COMMUNITY**

by

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BFA, Emily Carr Institute of Art and Design 2005

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THE REQUIREMENTS FOR THE DEGREE OF  
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## **ABSTRACT**

The goal of this research is to understand the role of agency, self-expression, and the process of producing collective intelligence in media works by novice directors through examining in detail a community-based media project. From 2005-07, the researcher was director of a media workshop for developmentally disabled adults who learned to direct their first video. Data from this workshop was examined using Strauss and Corbin's grounded theory and Clarke's situational analysis in order to identify the interactions between the directors, liaison and trainer, and the sponsoring organizations. In addition to applying new research methods to media and interactive arts, the work contributes to knowledge regarding the effectiveness of community-based adaptive education for non-mainstream learners based on communities of practice. As well as extending adaptive technology to education, the work interrogates inclusive community by analysing Warschauer's critique of the digital divide in order to include digital video production and editing access.

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## CHAPTER 1: INTRODUCTION

In the past decade, the lower cost of professional digital video production equipment and editing software has allowed a greater number of people to access the technology. Unfortunately, for individuals who lack higher education or disposable income, the development of media skills is still beyond their reach. In 2001, 27% of Canadians with disabilities had a college or university education, compared to 37% of non-disabled Canadians; 42% of people with disabilities were employed compared to the Canadian average of 74%; the average income of people with disabilities who were employed was \$17,158 compared to the Canadian average of \$31,509 (Statistics Canada, 2003). A provincial government report from 2003/04 states that:

There are over 500,000 British Columbians with disabilities. Approximately 350,000 are between the ages of 15 and 64 and considered of working age. While 44% of these individuals reported they were employed, 21% declared they were unemployed and 30% stated they were not in the labour market. The annual income range most frequently reported amongst persons with disabilities in BC was between \$10,000 and \$15,000. Women with disabilities on average earned 53% less than their non-disabled counterparts, while men with disabilities on average earned 63% less than non-disabled men (Province of British Columbia, 2004, para. 38-39).

This situation is especially acute for individuals with developmental or intellectual disabilities. Instead of adopting a purely medical viewpoint that seeks to eliminate disability, within this thesis I advocate for the social model, which looks for ways to support and accommodate participation by people with

disabilities, on their own terms. Through learning to use digital video equipment, people with developmental disabilities can be supported to find their voice and to encourage others to tell their stories. My research addresses social exclusion/inclusion and looks at the impact on “self-advocates” (a designation those with developmental disabilities prefer) becoming video directors.

Millions of individuals worldwide are potential contributors to a collective understanding of the human condition, exhibited on websites, through social networking software, and via digital video production. In the Prologue to *Collective Intelligence*, Pierre Lévy has written:

... if we are committed to the process of collective intelligence, we will gradually create the technologies, sign systems, forms of social organization and regulation that enable us to think as a group, concentrate our intellectual and spiritual forces, and negotiate practical real-time solutions to the complex problems we must inevitably confront (1997, p.xxvii).

While the tools that Lévy envisioned currently may be in place, their use may not be accessible to self-advocates. In her study of the adoption of assistive technology devices by young adults with cognitive disabilities, Melissa Dawe (2006) states that 35% or more of the devices are not adopted successfully.

Through analysing multiple viewpoints within the situation of a community-based media project, I examine how developmentally disabled adults who attended *this ability media club* learned to direct their first video production in order to critically assess the role of agency in self-expression. The agency necessary to direct their own video was not activated until the community media project provided a vehicle for expression, training, and exhibition. Multiple and

connected levels of interaction are interrogated to determine the relationships involved in community-based media creation – the participant/director (individuals who expressed themselves by directing a video), the instructor and liaison (individuals who instructed or assisted the directors), and the organizational/public policy (individual administrator or planning documents expressing a macro communication perspective). The stated intentions and actions of each level are analysed to reveal their effect on the others and to demonstrate how increased expression from the grassroots can affect both public policies and pedagogical design. When the videos are publicly exhibited, they challenge viewers' preconceptions regarding the abilities of self-advocates and elevate the social status of the directors. Additionally, voices that were silent can make a significant contribution to an evolving collective intelligence (Lévy, 1997; O'Reilly, 2005).

The community-based media project on which this research is centred is called *this ability media club*. From February 2005 to March 2007, the group met weekly to encourage creative self-expression by self-advocates. During the four previous years, the Burnaby Association for Community Inclusion (BACI), host of the *media club*, had undertaken a period of organizational renewal with representatives from *Philia – A Dialogue on Caring Citizenship*. From its origins in disability communities, *Philia* promotes “a notion of citizenship based on contribution, participation, relationship, and a commitment to the common good” (Philia, 2005a, para. 1). The involvement of *Philia*, a group that advocates for a renewed sense of community in relation to people with disabilities, elevated the

program from simple skills-based training to one that could help redefine citizenship. Inspired by ideals of the *Philia Dialogue*, the change at BACI reflected an organizational shift from being a service provider to hosting an inclusive and caring community (Smith, 2004). BACI's partner in the *media club* – the Pacific Regional office of the National Film Board of Canada (NFB) – was also engaged in a process of renewal in 2005. Their Director General had encouraged all regional offices to revitalize the spirit of *Challenge for Change*, an NFB program that originated in 1967.

In the best-known example of the program, residents of Fogo Island off Canada's Newfoundland coast were given equipment and technicians and were encouraged to communicate with each other and with the federal government in an effort to democratize media production. In response to the new form of filmmaking, the islanders' forced relocation was transformed into a number of community development programs that allowed them to continue living on Fogo. Inspired by the example of *Challenge for Change*, *this ability media club* also sought to promote social change by placing media tools in the hands of a marginalized community in a process-oriented project. Both groups found articulation as individuals and as a community through actions based on expressive agency. Unlike the Fogo Islanders, who were threatened with forced relocation by the Canadian government and responded to injustice through community engagement (Smith, 2004), the self-advocates were motivated more by the opportunity to increase their technical and public speaking skills and by the possibility of engaged employment. Although the *Challenge for Change*

program was sponsored by seven government departments, there was minimal intervention into the activities of Fogo Islanders, who used video to create a community dialogue or “feedback loop” (Smith, 2004, p. 12).

In order to advance public knowledge about people with disabilities, there must be a means of communication with others, a more structured form of interaction than living within the same geographic community. Although a traditional definition of community involves locale, this doesn't take into account belonging and contribution. Through creating media works and screening them publicly, the *media club* participants have extended the reach of the *Philia Dialogue*, demonstrating how people with disabilities contribute to their community and belong within it as equal citizens. In the planning document for *this ability*, Smith states that although contributions through action are important, presence can also be a form of contribution.

Simply by being present meaningful interaction, communion and fellowship is created. The exchange may be a helping hand, a spark of life, a moment of insight, the comfort of silence, a pleasurable experience, an inspiring interchange or a thrilling encounter. It would not have happened without your presence (2004 p. 8).

Guided by the philosophy of the *Philia Dialogue*, members of *this ability media club* were asked to investigate their own social contributions through media works. The media works that resulted from their participation have been used to encourage dialogue among communities of self-advocates and their supporters, as well as with an international audience through online distribution (National Film Board of Canada, 2006a).

Beginning in the summer of 2005, the participants worked with representatives from the NFB including the author, who assisted them in formulating a concept that eventually became a video production. In order to explore the concepts of citizenship, contribution, and community, two members of the group created works concerned with their workplace, one in a video store and the other at a coffeeshop. While one director scanned photos and interviewed his father, telling a story about their fishing trips together, another hoped to follow his parents' lead and start his own family. Another video followed a strict interview format: the director questioned his friend about growing up within a large institution and how he became a self-advocate when he was released into the community. The sixth video is an original video with an ecological message, encouraging the audience to be kind to spiders through drawing an analogy to the near-extinction of the buffalo on the western Canadian frontier. Several other members of the *media club* did not make videos but were able to participate through taking photographs and making hand shadows with the data projector. Everyone was encouraged to participate based on their own abilities.

A sense of agency is expressed when a person takes some form of action that leads to meaningful results. This process closely resembles that of becoming a self-advocate – a person who through self-expression is able to determine that actions taken are in their own best interest. Through comparing print-based with online second language acquisition, a recent publication concluded that “Authenticity and authorship have given way to agency and identity and the

presentation of self” (Kramsch et al., 2000, p. 78). Although poor print literacy may have been a barrier to members of *this ability media club*, I argue that self-presentation using digital video, supported by agentive authorship, is a way of representing one’s identity. The participation of self-advocates as directors was based on telling their own stories or the stories of those close to them.

As Mark Warschauer (2003) has observed, multimedia can empower users who express themselves best verbally or through physical movement. Unfortunately, because of the higher cost of multimedia equipment and software and the need for broadband Internet access, the means of expressing oneself by utilizing these tools is beyond the reach of many people with disabilities. According to Warschauer, this problematic situation is worthy of further study: “This discrepancy between the *potential* of multimedia literacy in promoting social inclusion and the unequal *access* to the tools and practices of multimedia literacy deserves attention” (2003, p. 116). The intention of *this ability media club* was to increase the media literacy of people who had not previously had an opportunity to increase their agency through finding their voice and expressing it in a digital form. As Warschauer argues, the debate over the digital divide has been reframed into strategies for social inclusion, which are also the intentions of both the *Philia Dialogue* and numerous community-based media and broadcast projects. Legacies of *this ability* include the video works that were created, increased public speaking opportunities for the directors, insight into teaching slow learners and the process of becoming a director, and empirically-based knowledge concerning the value of social contribution and participation.



## 1.1 Expressing agency

There are two extreme positions within a spectrum that examines the disability experience – the medical model that searches for a cure and the social model which asks a civil society to respond inclusively. The social model becomes active when people with disabilities are able to control their own living conditions and social mobility. An example of using and expressing agency through video production emerged in an interview with a self-advocate director. Because of his newly acquired video skills, he was invited to co-facilitate a workshop that taped self-advocates while they practiced speaking to their caregivers. Although the participants may have felt reluctant to speak up in the past, the goal of the workshop was to strengthen their voice in relation with authority through practicing and reviewing the video recording.

In conjunction with the social model, academic researchers and community organizations have investigated how technology can be adapted for people with disabilities (Tetra Society of North America, 2007; Dawe et al., 2005; Dawe, 2006). Few, however, have studied how education can be adapted for people with intellectual disabilities to make digital video production more accessible. Until self-advocates are able to freely access and utilize new technological forms, the expression of agency is moot, frustrated immediately by either a non-inclusive interface or an inappropriate tutorial approach. In the case of a video camera, having the buttons on the outside under manual control may be more accessible to people with certain disabilities, while for others using a touch sensitive screen is more accessible. When the development of adaptive

technology is coupled with an appropriate pedagogy, promises of social inclusion will come closer to reality.

In the context of access to the Internet, Warschauer (2003) notes that although Information and Communication Technology (ICT) has become more widely available, popular pedagogical instruction is relatively inaccessible. By adopting a learner-centred approach to digital video instruction, the knowledge gap in training marginalized learners to become directors has begun to be addressed, at least within the context of community-based media projects.

In order for *this ability media club* training to be effective, it was adapted to the learning needs of the self-advocate directors and included instruction in technical skills and techniques for self-expression and critical media analysis. Initially, the participants did not deal directly with policymakers or administrators, working instead with the instructor and liaison who enacted an intermediate level of mentorship, acting on sometimes abstract organizational policies while communicating with self-advocates in “plain language.” For example, the plain language version of “What does citizenship mean to you?” substitutes the word “community” for “citizenship”. During the period of refining and revising the media works, the administrators and policy makers gave feedback to the group through an Advisory Committee. Participating as advisors, members of the *Philia Dialogue* promoted the idea that social well-being is based on the participation of all citizens and must include a recognition of the contributions of people with disabilities.

When the media works from *this ability* were completed, they were launched into the public view in an event honouring the directors. Finding their voice through enacting the *Philia* philosophy, the directors articulated in media form the ways in which they contribute to society. Through ensuring the media works created are widely available, the organizational partners contribute to collective intelligence, especially in regard to the lives of people with developmental disabilities. Six videos were made by the self-advocate directors, and are publicly available on the NFB website CitizenShift (National Film Board of Canada, 2006).

If technological access and education is limited, the ability to create media artefacts is lessened, resulting in a marginalized community becoming further isolated. Of course, a community may choose to remain unexplored by outsiders and the ideology of mass media may differ from that of community media participants. However, "Multimedia and the Internet enable learners to find a voice for themselves at the intersection of multiple time scales, to represent their own version of reality through multimodal texts, and to confront a broad public audience with that reality" (Kramsch et al., 2000, p. 98). Within the current research project, a community-based video program structure was used to empower individual members, who in turned used their agency as novice directors to express their ideas through video creation.

Media works representing the voice of self-advocates were not generated spontaneously from their community; the voice creation activities were nurtured by an educational presentation that was adapted for them and by a sponsoring

organization that acknowledged a paradigm shift from providing support services to recognizing the contributions of all citizens. At the heart of this research project is the mapping and analysis of community-based media programs based on a grounded theory approach to *this ability media club*. *On becoming a director* deals with the perspectives within this form of exchange – with how the content of novice directors is constructed, especially those working in community-based production. The grounded theory analysis presented in this thesis is based on data from one group, *this ability media club*.

From the viewpoint of a researcher, I am demonstrating my own agency in the way that this project was constructed and through the research design and data selection. As Strauss and Corbin (1998) have noted, interplay between data and the researcher is part of the grounded theory methodology. In this case, I was also a part of creating the data, working as the sole technical mentor to the self-advocate directors. The liaison and I planned the program, with assistance from the Advisory Committee. The liaison was employed by the host organization BACI while I was employed by the NFB, the media partner. In Figure 1's conditional / consequential matrix, the structure of the program is organized around the movement of self-expression (videos created within the group) as the works become public. The individual participant/directors are at the centre of my version of Strauss and Corbin's analytic diagram. Table 1 presents a list of those who participated in the research. Anonymous contributors who were interviewed are identified by random initials; those who wrote planning documents or policy statements are identified by name.

## Becoming a director matrix



Based on Strauss & Corbin grounded theory conditional / consequential matrix

Figure 1: Diagram of becoming a director using conditional / consequential matrix.

Table 1: Contributors to *this ability media club* research and their roles

<b>Players and secondary source persons in this study</b>		
<b>Coding designation</b>	<b>Roles</b>	<b>Names or initials</b>
Participant/directors	participants	AZ, GG, TG, WS
Participant/liaison	liaison	OF
Participant/instructor	program director, researcher, documentary director	Lorna Boschman
Host organization	administrator	CH
Media partner	producer	Tracey Friesen.
<b>Secondary sources</b>		
<b>Persons</b>	<b>Material description</b>	<b>Title</b>
Tracey Friesen (2005)	internal media partner report on disability-related projects which involved the Pacific region national film studio	"Disability Projects, Initiatives and Community Outreach"
Avril Orloff (2005)	final report on project to integrate <i>Philia Dialogue</i> into host organization	"Philia at BACI: An Experiment in Organizational Transformation"
Brian Smith (2004)	commissioned by the NFB to write– a paper that discusses the feasibility of a media club for self-advocates.	"This Ability: Revealing the Contributions of People With Disabilities"

Using the arrows in the matrix, I showed the participant/director joining *this ability media club* and working with the participant/instructor and participant/liaison to create a video project. First, the video went through a critical analysis within the *media club* and the director agreed that no further changes were required. Next, the work was shown to the Advisory Committee, which consisted of community and media partners, including BACI, the NFB, *Philia Dialogue* representatives, and family members of the self-advocates. When the videos had the approval of the Advisory Committee, they were shown at community events and online through the NFB's CitizenShift site. BACI staff and the self-advocate directors also showed the videos in person at conferences and meetings; my matrix suggests that the combination of personal contact and screening represents a powerful method of convincing policymakers of the contributions of people with disabilities. The policymaker level, in turn, is in a position to advocate on behalf of the self-advocate community, as well as to promote community-based media projects encouraging other marginalized communities to communicate using digital video as a means of expression.

My interaction with the project was administrative, instructional, and authorial, as I directed a half hour documentary about the project that incorporated the six short works by self-advocates (Friesen & Boschman, 2006). In addition to being the project director of *this ability media club* and working with the organizational partners to create an adapted curriculum, I acted as a technical mentor to the self-advocate directors, assisting them in almost every aspect of the media process. Throughout the project, I attempted to remain true

to the intended meaning of the directors, verifying their intentions at every step. In many respects, my situation as a mentor to adults with cognitive disabilities did not differ greatly from the mentorship offered to any other director. Ethical decisions related to questions of how knowledge is constructed are part of many media productions, not just community-based media projects. Finally, the project allowed me to develop critical skills as a qualitative researcher, allowing me to look beyond creation and dissemination of the works in order to analyse the larger role of agency in self-expression.

## **1.2 Overview of key terms**

### **1.2.1 Agency**

In a literature overview based in linguistic anthropology, agency is defined as a concept that relates to and is affected by sociocultural conditions and the capacity to take action (Ahearn, 2001). Ahearn notes that while scholars associated with action theory tend to treat agency synonymously with free will, this understanding does not take into account the social nature of agency or the impact of culture in forming agentic relationships. Conversely, seeing agency solely as a form of social resistance does not take into account the effect of culture on individual agency.

Janet Murray discusses the confusion between authorship and agency in the context of game play. "The interactor is not the author of the digital narrative, although the interactor can experience...the thrill of exerting power over enticing



and plastic materials. This is not authorship but agency” (Murray, 1997, p.153).

Within this thesis, the agency of authors (directors) is under examination.

Adele Clarke discusses agency in relation to Foucault’s pioneering analysis of social power.

Discourses have agency... Yet a number of critiques of Foucault (including some feminist, materialist, and interactionist critiques) have centered on the absence of agency that itself allowed the absence of resistance to discourse in his work. That is, for Foucault in these works, human (and other) subjects were constituted through discourse but either did not respond to it (and were unagentic, were paralytic in the face of discourse, and/or were discourse itself) or their responses were not noted or included by Foucault... In very sharp contrast, in situational analysis, analyzing discourses through situational mapping instead seeks to represent *all of the major discourses related to the situation* of interest—not just what could be called “the master discourse,” that which usually trumps the others (2005, p. 174-175).

Following Clarke’s lead, this thesis examines all levels of discourse within *this ability media club*, in order to analyse the role of agency.

### 1.2.2 Citizenship

Following the principles of *Philia – A Dialogue on Caring Citizenship*, the definition of citizenship incorporated into this thesis recognizes the unique contributions of all citizens. A citizen is someone who contributes to one’s community; contributions may be as simple as being physically present or be as engaged as a political activist. At a *Philia Dialogue on Citizenship* panel, professor and former Chief Commissioner of the Ontario Human Rights Commission Catherine Frazee is quoted as saying (Philia, 2005b):

For people with disabilities, the notion of citizenship is bound up with questions of access and entitlement, and with processes and

structures that threaten to extinguish our identity and contribution. To be a citizen is to belong. At the intersection of disability and citizenship, we confront the essential question of our collective allegiance to a constitution of values (para. 5).

Clemencia Rodriguez has theorized that the real strength of alternative or non-mainstream communications initiatives (citizens' media) is that they allow participants to exercise their agency as citizens:

As defined by the theory of radical democracy, the concept of citizenship implies that social subjects claim a space for their public voices, that these social subjects tenaciously intervene and shape their identities, altering circulating social discourses and cultural codes, and that, as a result of the above, these negotiations and renegotiations empower the communities involved. Seen from a radical democracy perspective, citizens' media materialize as important sites where citizenship is forged. By participating in these media experiences, reshaping their identities, reformulating established social definitions, and legitimizing local cultures and lifestyles on the personal as well as the local level, communities are actively enacting citizenship (2001, p. 158).

### 1.2.3 Cognitive disabilities

Cognitive disabilities have been defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as qualities of individuals who are "significantly limited in at least two of the following areas: self-care, communication, home living, social/ interpersonal skills, self-direction, use of community resources, functional academic skills, work, leisure, health and safety" (as cited in Dawe, 2006). The host organization of *this ability media club*, the Burnaby Association for Community Inclusion (BACI), works with individuals who have been diagnosed with Downs syndrome, cerebral palsy, autistic spectrum disorder, and other cognitive or developmental disabilities. Rather than referring to individuals by their medical condition, representatives from within

these communities refer to themselves as self-advocates, an identity explored further in the definition below.

#### 1.2.4 Collective intelligence

The sense of collective or networked intelligence informing this work identifies the Internet's potential to bring people together in order to solve common problems. In 1997, Lévy wrote of the utopian potential of the Internet, which allows diverse communities worldwide to share knowledge with each other. He believed that human society is transitioning from the Cartesian individualist ideal to a more collective expression of individuality through shared contribution to a larger community (Lévy, 1997). Tim O'Reilly, the designer who helped to coin the phrase "Web 2.0" states that successful Internet sites are "harnessing collective intelligence" (O'Reilly, 2005). Within this thesis document, the dissemination of *this ability media club* video productions on the Internet is recognized as a contribution to collective intelligence. Discussions of collective intelligence by Lévy and O'Reilly fail to mention the economic and educational barriers to inclusion, raised by Warschauer and others in discussions of the digital divide. One of the distinctions of *this ability media club* is that it builds on the work of others, taking over where others have left off in order to promote social inclusion.

Drawing on precedents such as Computer-Supported Cooperative Work, Francis Heylighen wrote on the role that collective mental maps (CMM) play in collective intelligence:

We have defined collective intelligence as collective problem-solving ability. Problem solving ability requires a mental map, which represents the different problem states, actions, and preferences. Collective problem-solving therefore requires a collective mental map. Such a CMM is an external, shared memory, to which all members of the collective have some degree of read/write access (1999, p. 277).

Within this thesis, collective intelligence is examined in the context of the contribution of the videos directed by members of *this ability media club*. The videos represent an inside look at the lived experiences of people with developmental disabilities. Equally importantly, expressing themselves through video shifted the position of the self-advocate/directors within the collective memory map from a passive position – being observed –into subjects with agency.

### **1.2.5 Community**

In a paper presented at *CHI 2006*, Amy Bruckman noted that “community” has fuzzy boundaries because the prototypical image used to denote it is culturally constructed (2006). The pastoral nurturing community may be a utopian ideal but has little basis in reality. Traditional notions of community are based on geographic location, but modern transportation and communication technologies have extended the notion of community to include social groupings based on similar interests. Within the context of this thesis, “community” is used to denote both a geographical community and the community of interest surrounding self-advocates.

### 1.2.6 Digital divide

When the term “digital divide” was originally popularized by the US Clinton administration in 1996, it referred to the gap between those who had access to Information and Communication Technology (ICT), especially computers and the Internet, and those who did not. As Warchauer notes, terms of the debate have since shifted. In 2000, the US government agency that originally popularized the digital divide published *Falling Through the Net: Toward Digital Inclusion* (United States Department of Commerce, 2000), a report that included data on US citizens with disabilities for the first time.

Technology offers enormous potential to increase the rates of computer and Internet use among people with disabilities. But technology can also be an additional barrier if products are not designed to be accessible. Innovations in the private sector as well as support from public entities are helping to ensure that more people have access to the Information Age by developing hardware and designing Web sites that are accessible to and usable by everyone (para. 6).

While computers and Internet access were already available for the use of the directors of *this ability*, video production equipment, digital editing software, and instruction based on a customized learning style were not.

### 1.2.7 Director

In the world of professional video production, a director is the member of the crew who guides actors and interview subjects, encouraging a performance or response that can be incorporated into the final video artefact. Crew members are also guided by the director to create an image or recording that is of sufficient quality to satisfy both the financial backers and future viewers of the production.

During the post-production phase, the director oversees the editing process to ensure that the finished video conforms to expectations. Within *this ability media club*, the self-advocate directors were involved in all aspects of the production; their approval was reached at several stages of post-production to ensure that the finished video met their expectations, within the budgetary restraints of the project. In a sense, the director is someone who imagines a different way of presenting information and then acts to ensure the story is told.

### **1.2.8 Self-advocacy**

According to the *British Columbia Association for Community Inclusion* (n.d.a): "Self Advocacy means speaking up and speaking out for your rights. Many people with developmental disabilities who are speaking up for their rights call themselves "self advocates."" This definition recognizes the ability of people with cognitive disabilities to use their voices to communicate their needs and asks that society accommodate those needs.

A British website representing *People First*, the international organization led by people with developmental disabilities, suggests that:

Self advocacy is people with learning difficulties speaking up for ourselves. Self advocacy is important because many people with learning difficulties spend their lives being told what to do. If you are always told what to do and never listened to you can get to the point where you don't even know how to make a decision for yourself. Speaking up is something people with learning difficulties need support to learn to do and other people need to learn how to understand us (n.d., para. 1).

### 1.2.9 Self-expression

Within this thesis, a creative statement of identity by the self-advocate directors has been examined. *This ability media club* encouraged the development of a form of agency that led to the creation of a media artefact by most participants in the group. The videos were a product of reflection on the director's contribution and inclusion in community.

## 1.3 Thesis structure

In this chapter, the larger thesis question and empirical context have been introduced. The concept of agency was explored in detail, in order to demonstrate how the concept connects an empirical grounded theory analysis with published academic literature. The chapter concluded with a discussion of key terms used within the thesis.

Chapter 2 is divided into three sections. In the first, the discussion begins with the digital divide discourse, from its examination of the unequal distribution of ICTs to current initiatives targeting social inclusion. Approaches to community-based media production are then analysed, and Rodriguez' term "citizens' media" is introduced. In the second section, literature about the history of self-advocacy in North America and the importance of self-determination are highlighted. The third section examines the role of agency, self-expression, and collective intelligence in community-based media or citizens' media projects.

Chapter 3 discusses in detail the research methods used to conduct workshops and to collect and analyse data, beginning with a public health

technique that informed this project's approach to community storytelling – Caroline Wang's *photovoice*. Although a variety of grounded theory approaches were considered, this study uses Strauss and Corbin's (1998) version of grounded theory, as outlined in the second edition of Basics of Qualitative Research. While exceptional in the development of coding and categorization, their methods are geared toward the analysis of individuals or groups and their activities and relationships. Clarke's (2005) new version of grounded theory, Situational Analysis goes beyond the conditional matrix to examine the discourse inherent within each situation. Through allowing grounded theory to explicitly contain the situation, a more complete picture of the context and ideas within each position has emerged.

In Chapter 4, a summary of the findings from the grounded theory study of *this ability media club* are presented. Structured around categories that emerged from the data, statements are from the three levels of interaction: the participant/director, the liaison and trainer, and the organizational/public policy. Together, they form a more complete picture of the community of support and multiple interactions that allowed participants to become directors and to encourage others to tell their own stories. In following grounded theory practice, the findings from the data formed the initial thesis content. Although presented earlier in the thesis, analysis of the contextual themes followed the research and were grounded in the emergent data.

Chapter 5 presents a summary of my arguments and conclusions, leading to a discussion of related areas worthy of future research. Through creating their



own media works, members of marginalized communities enact their citizenship and contribute to their own social power by creating alternative representations of themselves and their communities.

## CHAPTER 2: CONCEPTUAL THEMES

Literature dealing precisely with the question of media expression and training for adults with developmental disabilities is scant. However, after analyzing the data using a grounded theory methodology, many of the questions raised by studying *this ability media club* can be linked back to existing academic discourse. Discussions of social inclusion in relation to the digital divide have tended to focus on computers and Internet access while avoiding a discussion of increasing public access to video production equipment. Community-based broadcast and participatory media programs may provide limited access to equipment and training but may not be able to support the slower pace and adapted training required by self-advocate learners. Both Warschauer (2003) and Carpentier (2003) have written that the debate has shifted from simple access to ease and purpose of use.

Attempts to make media creation more accessible to a general public do not address the level of support needed by self-advocate learners, nor do they provide training that is accessible to these potential directors. Programs such as *this ability media club* are attempts to democratize media production for a marginalized community. Funded by a government media agency, the program increased access and facilitated exhibition in an attempt to address the lack of access and training in digital video production techniques. Traditional methods of

instruction provide barriers for self-advocates, especially those who have low literacy levels, low tolerance for abstract teaching methods, or minimal verbal skills.

## **2.1 Extending the digital divide discourse to community media**

In Technology and Social Inclusion, Warschauer presents his critique of social policy based on the digital divide ideology and explores the relationship between Information and Communication Technology (ICT) and social inclusion (2003). Today's information economy is based on the understanding and comfort in use of ICT; marginalization may result from a lack of access to ICT or from inadequate training in its use (Warschauer, 2003). Programs that encourage further access to ICT contribute to networked communities that can enhance human society by allowing individuals to be included who may previously have been isolated. For people with disabilities, the implications of developing skills with common ICTs could be profound, offering greater mobility socially and economically. At the same time, those who have been economically marginalized are the least able to afford current ICT hardware and training. Additionally, curriculum for those with developmental disabilities has not been developed specifically for media and ICT training, making *this ability media club* a timely intervention in community development. Warschauer (2003) observes that: "Content and language, literacy and education, and community and institutional structures must all be taken into account if meaningful access to new technologies is to be provided" (p. 6).

Lacking from much of the digital divide discourse is the importance of access to video production equipment and editing software, and the potential for contribution through training people with development disabilities in these technologies. While lower-end computers and dial-up Internet access are becoming more widely available in industrialized countries, programs that go beyond print-based to digital media literacy are less common. Training non-professionals in broadcast technologies has been achieved to an extent by community television and radio stations. A weekly program hosted by self-advocates, *The Community Living Show*, broadcasts weekly from Vancouver's *Co-operative Radio* (British Columbia Association for Community Living, n.d.b). In Canada, the NFB has encouraged women, indigenous people, and other groups who have traditionally not represented themselves in media to find their voice and become filmmakers. Their distribution network disseminates the work, promoting NFB productions to markets such as commercial and educational broadcasters, festivals, the educational market, and sales to individuals. At the same time as the NFB was assisting *this ability media club*, they were also involved in a digital storytelling project with Vancouver seniors *Life Stories: Gifts of Experience* and one with youth in a low income area of Surrey BC (National Film Board of Canada, 2006b; National Film Board of Canada, 2006c).

Funded by Britain's public broadcaster BBC, *Video Nation* began screening short videos from its experiment in community-based television in 1994. Originally 50 non-professional participants were trained in the use of video equipment and were asked to submit footage regularly in exchange for free use

of the equipment. *Video Nation* staff members edited the footage into short portraits, over which the director had a veto prior to broadcast (Carpentier, 2003). Utilizing a participatory approach, the short video portraits “aim to signify the multilayered culture of ‘ordinary people’ and the cultural diversity within the British nation” (Carpentier, 2003, p. 426). During the original broadcast phase of the program, over 10,000 tapes were shot, resulting in 1,300 short edited videos that were shown on primetime television (BBC, 2007b). After television broadcasts of the program ended, the footage was re-purposed for an online site (see: <http://bbc.co.uk/videonation>). Currently, new participants are provided with a camera and more limited training than during the broadcast years (Carpentier, 2003).

Carpentier (2003) notes that community media projects have attempted to increase social participation, allowing communities that have previously been misrepresented to create media on their own terms. A search of *Video Nation's* archives on June 15, 2007 using the term “disability” brought up 48 works but without knowing more about the directors, it is difficult to determine if any of the participants/directors are people with intellectual or developmental disabilities. Without the investment of resources and support infrastructure aimed at training a specific community as was the case with *this ability*, it seems less likely that a large number of adults with developmental disabilities would participate in *Video Nation*, which was aimed at “ordinary people”.

Ellie Rennie (2006) discusses the implications of the shifting mediascape from analogue broadcast to digital distribution via the Internet. Noting that the

words used to refer to the phenomena differ from one geographic area to another, Rennie (2006) defines community media in this way: “The terms “participation” and “access” apply to most community media endeavors, meaning that non-professional media makers are encouraged to become involved (participation), providing individuals and communities with a platform to express their views (access)” (p. 3). When community media use analogue broadcast channels, they are regulated in the same ways as commercial content providers. Spectrum scarcity, or the lack of available bandwidth, has led to further marginalization of non-commercial broadcasters. However, compressed digital video files can be distributed without regulation via the Internet. If a group is willing to sacrifice some control over file compression, video clips can even be uploaded and stored on sites like YouTube (see: <http://youtube.com>). A link to the digital video stored on YouTube can be embedded within a webpage of the community media site.

Rennie (2006) points out that Rodriguez reframed both community-based media and alternative media as citizens’ media. Rodriguez (2001) notes that the term alternative media cannot contain the variety of groups that could be identified that way. The concept of “alternative” suggests a binary adversarial relationship with mainstream media, a popularity contest where the “alternative” with its smaller audience is not likely to succeed. Rodriguez’ (2001) approach applies the concepts of power and democracy developed by feminist scholars Chantal Mouffe and Kristie McClure to community-based media production: “...alternative media spin transformative processes that alter people’s senses of

self, their subjective positionings, and therefore their access to power” (p. 18). In presenting citizens’ media as a more accurate way to represent the processes involved, Rodriguez continues:

Conversely, referring to “citizens’ media” implies first that a collectivity is *enacting* its citizenship by actively intervening and transforming the established mediascape; second, that these media are contesting social codes, legitimized identities, and institutionalized social relations; and third, that these communication practices are empowering the community involved, to the point where these transformations and changes are possible (2001, p. 20).

While the forms of dissemination and the makeup of audiences differ from project to project, community-based video productions created for broadcast or online distribution are similar in that they encourage perspectives and situations not commonly replicated in mainstream media programming. By applying the citizens’ media concept to community-based media projects, the power of being a director is exposed. Not only is a community hosting citizens’ media empowered but the individual who finds self-expression is as well because of her/his shifting social identity. Although finding an audience is an important step for content creators, this thesis focuses on directors’ active experience of formulating the work and on social structures that support expression by individuals from marginalized communities. The question of attracting an audience is more important to commercial broadcasters’ continued survival; the focus of citizens’ media is on the content being the expression of self by the person who made it or a representation of the community itself.

An internal National Film Board report written by Tracey Friesen (2005) discussed eleven different initiatives undertaken by the Pacific region's office to support filmmakers with disabilities. The internal NFB characterization of activities involving filmmakers with disabilities presented to producers and administrators of Canada's national documentary studio echoes the communications strategies of citizens' media, allowing voices to be heard that weren't represented elsewhere.

For many of my colleagues, this pattern is familiar. There was Studio D and the feminist film movement in the 70s, when women insisted it was time to move beyond a male perspective on women's realities. They maintained that they needed to tell their stories, from their own perspectives. Then the NFB spearheaded an Aboriginal Filmmaking Program and supported the launch of many successful directing careers. A commitment to cultural diversity over the last several years has ensured that a greater variety of voices continues to be heard through our audio-visual creations. (2005, p. 5)

Rather than examining content and its authenticity, *On becoming a director* seeks to examine the process of directors finding their voice and the structures that support the act of filmmaking by novices. As participants in *this ability* have noted, they did not join the project with the intention of becoming directors. Instead they became directors through participating in the program, one that combined skill development, the opportunity to find expression in media form, and an environment customized to their learning style. To compare the process of becoming a *this ability media club* director with established methods of training of media students does not address the support required by self-advocates to participate fully in the learning process. Instead, the project under



study will be compared to the process undertaken in making community-based participatory videos.

Like videos made through community-based participatory research, *this ability* videos and the process of making them are more tied to community development than with creating entertainment for a mass audience. As a result of creating their videos, the directors have not been invited to film festivals. Instead, they have been asked to participate in BACI staff orientation, training programs for other self-advocates, and to be speakers engaged in public education. Instead of examining their success in the terms of film industry recognition, the area under examination is their social contribution, sense of belonging, and engagement with the geographic community, as well as with communities with similar interests.

While the definition of ICTs that are publicly available could be extended to include digital video production and editing gear, the resources of citizens' media could be further extended toward inclusion of self-advocates. Until access is universal to learner-appropriate equipment and skills development, the full participation of individuals with disabilities is not assured. In order to further develop ideas on the creation of an environment that would encourage self-advocates to express agency through becoming media directors, it is necessary to further investigate the history of self-advocacy in North America.

## 2.2 On self-advocates and self-determination

“Mental retardation” is not a term commonly used by individuals who work closely with self-advocates because of its negative connotations although the term frequently appears in medical literature as the diagnosis given to people with developmental disabilities. The history of those who have been diagnosed as mentally retarded in the US has been characterized by three waves of influence: *professionalism* in the early 20<sup>th</sup> Century, *parents* following the Second World War and *self-advocates* following the civil rights movement of the 1970’s (Wehmeyer et al., 2000). Self-advocates were viewed as a threat to society – the earlier professional characterization of self-advocates was as sub-human and as individuals who were prone to criminal activities. It was during the early 20<sup>th</sup> Century that the eugenics movement became popular, resulting in legislation that allowed sterilization of those who were diagnosed as mentally retarded. In Canada, the B.C. Eugenics Board operated from 1933 to 1979, overseeing the forced sterilization of self-advocates who were institutionalized during that time (British Columbia Association for Community Living, n.d.c). Professionals used intelligence tests to determine who would be institutionalized, removing basic civil rights from those who scored poorly (Wehmeyer, Bersani et al., 2000). The authors characterize the professional era in this way:

At the height of the First Wave, professionals defined the issues and created the then-new discipline of mental retardation as separate from the fields of medicine, psychology, and education... The emphasis was on diagnosis and, particularly with the growing popularity of intelligence testing, in determining who would benefit from treatment (or not). A person labelled with mental retardation had no basic civil rights, from education to the opportunity to enlist in the military service. (p. 107)

Within this paradigm, people with disabilities were to be fixed by treatment, leading many to adopt a medical model of disability. Wehmeyer et al. (2000) note that based on intelligence testing, the mental age of adults was calculated, leading some to consider self-advocates as “perpetual children” or “holy innocents” (p. 107). By the late 1940’s, medical advances, treatment options, and the return of disabled WWII veterans had begun to change public attitudes. No longer content to allow the medical profession to make all of the decisions, parents of children with developmental disabilities began to demand more community services for their children (Wehmeyer, Bersani et al., 2000). The host organization of *this ability media club*, BACI was formed in 1956 by parents of self-advocates who were not allowed into the public school system (Smith, 2004).

In the early 1940’s, the study of human behaviour developed into a discipline called personality psychology (Wehmeyer, Bersani et al., 2000). An important question was determinism – How do internal human traits affect personality? – resulting in the examination of self-determination. In “The Right to Self-Determination”, Kirje suggests that the normalization principle be applied in order that self-advocates could experience the social rights and responsibilities that other citizens take for granted (Kirje as cited in Wehmeyer et al., 2000) As self-advocates born during the baby boom era matured, they began to speak for themselves and demand greater social freedom. Beginning in 1965, groups of people who had been diagnosed with the label mental retardation met in Sweden

to discuss their rights (Wehmeyer, Bersani et al., 2000). The international organization of self-advocates, *People First* began in Oregon in 1982.

Professionals and caregivers began to recognize that self-advocates could speak for themselves. Enhancing the capacity of self-advocates to participate fully in society is related to both the development of skills and the opportunity for self-determination (Wehmeyer, Bersani et al., 2000). The move toward self-advocacy was also characterized by the North American closure of large institutions which had previously housed many people with cognitive disabilities (Dawe, Fischer et al., 2005). Today individuals who spent significant portions of their childhood within an institution because of their diagnosis are able to live within the community at large, supported by their friends and families, as well as by social service organizations like BACI.

Today North American students with disabilities have access to public education. Susan Palmer et al. have written that the US...

1997 Amendments (Public Law 105-17) to the Individuals With Disabilities Education Act (IDEA) required that the individualized education program (IEP) of *all* students receiving special education services include (a) statements describing how the child's disability affects his or her involvement and progress in the general curriculum; (b) measurable goals to enable the child to be involved in and progress in the general curriculum; and (c) services, program modifications, and supports necessary for the child to be involved in and progress in the general curriculum. (2004, p. 427)

The legislation requires that the general curriculum be accessible for all students, including those with developmental or intellectual disabilities. Palmer's research suggests that a way to increase involvement for these learners is to train them to build their capacity for self-determination. Arguing that state

standards often require skills in areas like “goal setting, problem-solving, and decision making,” the authors note that “self-determination is a form of curriculum augmentation that enables students to learn and then apply skills that support their enhanced self-direction of learning. (Palmer, Wehmeyer et al., 2004, p. 428)” The concept of normalization has been integrated into all aspects of the lives of people with intellectual and developmental disabilities. If the Third Wave of self-advocacy was led by baby boomers as they left institutions and began to live in the general community, the Fourth Wave will surely be led by self-advocates who have been integrated into mainstream classrooms and who are now attending university.

### **2.3 Understanding contribution: Collective intelligence and citizens' media**

What is the role of agency, self-expression, and collective intelligence in community-based media projects? How do the contributions of participants, especially those with intellectual or developmental disabilities improve or enhance our collective social experience? As Wehmeyer (2000) and Palmer (2004) argue, building a capacity for self-determination is key to the advancement of people with developmental disabilities. Adaptive training in goal setting and decision making allowed young self-advocates to participate fully in the general school curriculum. Agency and self-expression are related to the development of self-determination and leadership skills, not just for self-advocates but for all learners. The tasks of a director include many of the same activities, including planning, decision-making, and understanding how to achieve

goals that have been set during the planning phase. As Alhearn (2001) suggests, agency is not just an individual trait, it is part of a recursive social relationship with culture. Discussions of citizens' media and participatory video research projects seem closest to the model adopted by *this ability*, and shed light on the infrastructure necessary to support self-expression by participants using digital video technology. Looking beyond the advantages accrued to the novice director and community, what are the larger social benefits of increasing access to video production and editing equipment for people who have been marginalized?

Returning to parallel debates surrounding access to the Internet, Michael Gurstein (2003) asserts that local communities should be able to customize the use of Information and Communication Technology (ICT) to serve their own needs. Too often, Gurstein (2003) notes, simply providing access to the Internet has followed the broadcast model, where access is provided but effective use is not considered.

However, ICTs are different. Once available, they can readily become not simply deliverers of content (to those with "access"), but also and crucially they can become the means for the production, distribution, and sale of "content" locally or globally; and, moreover, beyond content, they provide the basic infrastructure for production, distribution, sales and service delivery in any area of activity which has a significant information, knowledge or learning component (*Achieving effective use*, para. 2).

On *Video Nation's* website, the format of the shorts shown is referred to as a "Video Diary" (BBC, 2007b). Like *YouTube*, visitors can upload short video clips to share with the portion of the world that has access to broadband Internet. Although the quality is sufficient only for Internet distribution, the portable

cameras and microphone accessories of laptop computers can be used to compose popular Video Diaries. The current wave of social networking software referred to as Web 2.0 involves "harnessing collective intelligence," allowing individuals and groups to share video, digital stills, audio, and written materials with anyone in the network (O'Reilly, 2006, para. 1). While earlier theorists like Lévy only imagined the power for collective intelligence that the Internet might have, current designers like O'Reilly have applied utopian concepts pragmatically:

If an essential part of Web 2.0 is harnessing collective intelligence, turning the web into a kind of global brain, the blogosphere is the equivalent of constant mental chatter in the forebrain, the voice we hear in all of our heads. It may not reflect the deep structure of the brain, which is often unconscious, but is instead the equivalent of conscious thought. And as a reflection of conscious thought and attention, the blogosphere has begun to have a powerful effect. (2005b, para. 11)

However, both O'Reilly and Lévy assume that access to Web 2.0 and the opportunity to contribute to collective intelligence are widely available. Unless access to ICT hardware, software, and appropriate pedagogical approaches to learning are universal, the input to collective intelligence will be skewed in favour of those with existing access. As important as the access to ICTs are, arguments that use only a rights-based approach are limited, according to Gurstein (2003).

Access to these production tools in the absence of the availability of the larger context of infrastructure, training, regulation, and others would render the value of such simple "access" meaningless except as an enhancement of the opportunity to participate in the Information Society as a passive consumer of information goods, however much the means to "communicate" might be enshrined and available as "rights" to end users. (*Effective use and communications rights*, para. 5)

Through pursuing a strategy that includes access and training in both technology and self-determination/agency, citizens' media programs can ensure that their own interpretations become part of the social discourse. As Rodriguez (2001) states:

...most citizens' groups which are involved with media production experiences are situated in subordinate relationships with respect to hegemonic social forces...However, by forging their cultural identities into texts for their own programming, citizens' media shift the balance of the subordinate/dominant cultural relationships. (p. 153)

Observing that although many citizens' media projects have a short lifespan, Rodriguez (2001) suggests that their accomplishments "can probably best be understood as those of empowered citizens who continue acting on their newfound abilities in a different realm" (p. 159). Arguing that citizens' media can take many forms, she concludes: "our attempts to define citizens' media should focus on the citizens, and their creative intentionality in altering the mediascape rather than centering on the external and objective forms citizens' media can take" (Rodriguez, 2001, p. 165). While becoming a director is connected to social inclusion and citizenship, the argument within this thesis is that the form and structure of the workshop gained in importance because it was geared specifically to the needs of self-advocate learners.



## CHAPTER 3: RESEARCH METHODS AND PROCEDURE

Since the current investigation into media creation activities inherent in community-based media is empirical and evolving, an inquiry into research methods has played a large role in the investigation. The primary research focus has been on adapting grounded theory, a method first developed in sociology, for use in multidisciplinary interactive arts and technology. Since sociologists and researchers from other disciplines studying social interaction have used grounded theory (Charmaz, 2005; Clarke, 2005; Dawe, Fischer et al., 2005; Ekins, 1997; Goulding, 2002; Strauss & Corbin, 1998) and since grounded theory has been described as especially suited to the qualitative study of group process (Charmaz, 2005), the methodology fits well with my research into modes of interaction by the individuals and organizations surrounding *this ability media club*. Charmaz (2005) has written: “We not only assume human agency but also study it and its consequences” (p. 523) and “Agency does not occur in isolation; it always arises within a social context already shaped by language, meaning, and modes of interaction” (p. 524).

In order to study the role of agency and self-expression within the process of becoming a director and to map the contributions of individuals and organizations that contribute to collective intelligence, it was necessary to find a research method that could incorporate diverse perspectives. Transcripts of

interviews with three participant/directors, the participant/liaison, and an administrator were coded, in addition to field notes, journals, and planning documents. All of these viewpoints and categorized actions were combined within this study through a structured framework. Grounded theory consists of a series of analytic procedures, allowing the researcher to move from descriptive elements of data into abstract constructions. Further interrogation of the data leads to an analysis, which is then compared to literature. Following the Chicago School qualitative research tradition of pragmatism, information derived from empirical field data is used to construct an applied theory grounded in that data yet recognizable to the community members. Because of grounded theory techniques, the evolving analytic storyline can be tested with the contributors themselves, in order to refine its veracity.

In order to gain a deeper understanding of the data that came out of *this ability media club*, a number of grounded theory analytic tools were utilised. The form of coding and analysis applied to the data was based on techniques described in Strauss and Corbin's second edition Basics of Qualitative Research (1998). Additional analytic tools and analysis is based on the research of a sociologist trained by Strauss, Adele Clarke. Clarke (2005) questions how the grounded theory conditional matrix (an analytic map of the areas under study) is constructed.

Strauss and Corbin advocated constructing a specific conditional matrix for each study (perhaps more than one) and tracing conditional paths for different stories/situations in the data... To me, the conditional matrices do not do the conceptual analytic work Strauss wanted done in terms of grounded theory method. Strauss was gesturing too abstractly toward the possible salience of the

structural elements of situations rather than insisting upon their concrete and detailed empirical specification and clear explication as a requisite part of grounded theory *analysis*. (p. 71)

In order to create a more concrete view of the areas under analysis, I have tried to include contextual information as well, like the historic conditions of self-advocates in North America. As Clarke (2005) advises, when I completed the classic grounded theory analysis of the data utilizing Strauss and Corbin's methods up to the point of the conditional matrix, I began to consider the discursive aspects of the situation.

The data collected from those surrounding and actively involved in *this ability media club* include multiple interviews with participants, instructor, liaison, and administrators, two sets of journals and field notes taken during the two-year history of the *media club*, and planning documents from the host and media organizations. By using a number of Strauss and Corbin's analytic techniques, the roles and actions of those within the situation will be defined and examined. Clarke's situational analysis method will bring the levels back together again, taking into account the multiple perspectives within the group. Through mapping these points of view, a fuller picture will emerge of the process of nurturing the abilities of emerging directors. Additionally, the investigation reveals ways in which the expressive voice of novice directors was constructed in relation to a marginalized community.

While grounded theory was used during the second year of *this ability media club* to investigate and analyse the actions of participants and the various viewpoints represented, another methodology influenced the initial states of the

community-based video project. During the first year, guidelines from *photovoice* a public health research methodology were adapted for video from the original photo-based approach (Wang, 2005). While *photovoice* is an action research method and the *media club* is not, many of the principles that encouraged self-expression by grassroots community members are applicable. Additionally, the concept of encouraging critical discourse within the group and actively disseminating results to policy-makers are important ones within this context.

### **3.1 Photovoice**

#### **3.1.1 Photovoice principles**

Photovoice is a participatory action research (PAR) method, first developed by public health researchers Wang and Burris for a project involving village women in Yunnan Province, China (Wang, 1999). PAR projects have common approaches: The participants are partners with the researcher, the entire group decides which images reflect the concerns of their constituency, the images reflect social as well as individual concerns, and the members are empowered by creating media objects based on critical reflection (Berg, 1995/2004). The *photovoice* method allows individuals who are lacking in social power to influence public policy through photography, utilizing the representational power of the visual to give voice to common concerns (Wang, 2005). *Photovoice* encourages participants to record the strengths and weaknesses of their local community, to discuss issues of interest or concern with other participants, and to influence public policy by involving community leaders and policymakers. As Wang, the co-creator of the method says, "What

experts think is important may not match what people at the grassroots think is important” (Wang, 2005).

*Photovoice* asset mapping/analysis and community-based media programs share a primary characteristic: they allow participants from marginalized communities to express themselves in ways that are personally empowering. According to *Photovoice Ethics*, participants must sign consent forms before shooting photographs; the images cannot be used to misrepresent the subjects (Wang and Redwood-Jones, 2001). Areas of social concern that have been addressed by *photovoice* researchers range from women’s health issues in a low income community near San Francisco, California to the social participation of youth in Flint, Michigan (Wang, 1999). In the method, researchers work in partnership with community organizations to involve participants. Each individual is given an inexpensive camera and is asked to record images in order to raise issues within the group and with policymakers, and to affect social change within the area. The expertise of people from the neighbourhood is acknowledged; their viewpoints supplement those of professionals who work within the community. As well as sharing the photographs with researchers and policymakers, public exhibition of the images allows the community to come together in recognition of the participants.

*Photovoice* draws on the tradition of education for critical consciousness, as formulated by the Brazilian educator and theorist Paulo Freire (1970/2000). According to this philosophy, it is important to encourage people to speak about the conditions within their own environment and how this relates to the lives of

those around them (Wang and Pies, 2004). In developing a critical consciousness, one begins to understand that recognizing words is only part of literacy. If the learner is still unable to discern misleading statements about one's own condition, a state of illiteracy continues.

Part of the *photovoice* method is to share selected photos with the group and with the researchers. Participants are asked to select one or two shots from each roll of film and to write informally about it. Questions are asked in relation to the image, centred on the mnemonic "SHOWeD": "What do you **See** here? What is really **Happening**? How does this relate to **Our** lives? **Why** does this problem or strength **exist**? What can we **Do** about it?" (Wang and Redwood-Jones, 2001) The group discusses what has been shot and what the images say about the community prior to exhibition or publication.

### **3.1.2 Applying *photovoice* to *this ability media club***

*Photovoice* as a public health methodology placed cameras in the hands of participants, training them to use the equipment and to understand the ethical parameters of photographic representation. *This ability* offered digital video and editing software training, adapted teaching methods, access to equipment, and mentorship for adults with developmental disabilities. Both approaches encouraged a critical dialogue about the work prior to exhibition. Both could be considered citizens' media in that they encouraged community members to engage in an examination of their lives. A major difference in the two approaches is that one uses text and still images to communicate, while the other used digital video. Chantal Akerman, a media and installation director, spoke of the

difference between her media-based interpretation and the earlier historic photographs depicting the Holocaust.

I want to return to discussing images of the camps, because the Americans took some images of the camps when they arrived there. When you see those images, they are totally frightening and horrifying, of people totally destroyed. With the image alone it is not possible to be totally aware of what it was for the people to be in that situation. In a way images are foreclosing, and it's totally right for an extreme case, because images will never say what the people have gone through. In a way that's why you should have other strategies to speak about it (2001, para. 26)

Within *this ability*, video is not used as a research method; instead it allowed the directors to express themselves by forming a visual story. *Photovoice* techniques were adapted to help *this ability* directors find their own stories. Grounded theory methods were used to analyse interviews with *this ability media club* participants and administrators, in order to form a more complete picture of the situation that encouraged the directors to find self-expression through enacting agency.

## 3.2 Grounded theory

### 3.2.1 Data collection and initial analysis

The grounded theory research process alternates between data collection and analysis, with questions that arise from the data informing further investigation in an iterative process. Within this study, interviews began with the participants in *this ability media club*, including three directors and the BACI liaison. As the materials were transcribed, the grounded theory activity of memoing began. Memos are notes written by the researcher, generated by ideas

that grow out of examining the data. Weekly group meetings were also recorded and descriptive field notes were written about the project. Once the interviews were transcribed, they were coded, first for category and then for activity; memos were written throughout the coding process, noting the patterns formed by the original materials.

Initial interviews with *media club* participants ranged in length from ten minutes to over an hour. Subsequent interviews began with verification and approval of the previous transcripts and sought to establish the validity of the research interpretation, both in transcription and coding, from the subjects. All research participants were re-interviewed in order to assess the emerging categories, to test the research storyline, and to allow further input into the interpretation. Subsequent interview questions also sought to clarify for the researcher any ambiguity that arose during previous discussions. Later interviews provided opportunities to test ideas that had emerged from the earlier data.

Interviews were transcribed from recordings made of a live conversation between the researcher and the participant. Although there was a list of questions related to the research problem, the interview was driven by the interests and observations of the respondent. The previously prepared questions were used when the respondent had nothing else to say generally on the subject. Analysis of the interview materials began with participant/directors and participant/liaison and then proceeded to interviews with the administrators of the host organization in order to establish categories from the self-advocates'



perspective. Finally, the field notes and journals were analyzed based on the categories that emerged from the interviews. Background information and the literature review were derived from themes that emerged from the respondent interviews. Additional interpretations emerged from the constant comparison of data, guided by the practice of writing memos.

The process of conducting grounded theory research is immersive – the researcher's ideas are shaped by the data, but the researcher must also be sensitive to the area under study so that the correct interpretation is selected. For example, by comparing data such as the opinions expressed by the three directors, dimensions of the activity BECOMING A DIRECTOR were clarified with respect to the project under study. The process begins with specific situations or statements, and subsequently asks the researcher to generalize from the data to form a tentative theory, which is then tested against the data and rechecked with respondents. Further data collection to clarify categories, dimensions, and interpretation is called theoretical sampling, and is another important step in expanding the emerging grounded theory. Clarke (2005) points out that the usual approach to grounded theory is to seek multiple meanings for the category and compare them:

Multiple readings are routinely and explicitly sought and produced through group effort. This is also the usual pedagogical tradition for teaching/learning grounded theory—to bring multiple perspectives together so that you can *more easily* produce multiple readings, multiple possible codes... Later in the research process, of course, the analyst will need to negotiate among the multiple readings produced to decide on those to be preserved and pursued through further theoretical sampling and final analytic products. But this does *not* mean reduction to a singular interpretation or representation (or a single basic social process). (p. 8)

### 3.2.2 Coding for concept and process

In the Strauss and Corbin method, the initial approach to the data is from a microanalysis or word-by-word perspective. By examining the first transcript of a participant/director's words, a number of categories related to the area under study emerged. With each interview, additional descriptive concepts were identified and previously identified ones were clarified. The ideas expressed which connected to the research question remained, to be used in comparison with the next interview. Presented alphabetically, categories included the following concepts: AWARD, COMMUNITY ART PROJECT, DECISION-MAKING, EMPLOYMENT, ETHICS, FRIENDSHIP, FUTURE PROJECTS, HIRING PROCESS, HOST ORGANIZATION, LARGE INSTITUTIONS, MEDIA ART THEME, MEDIA CLUB, MEDIA CLUB DIRECTOR, MODEL, NETWORKING, NOTES, PERSONAL STORY, SELF-ADVOCATE, SHARED LEARNING, SUPPORT, TEAMWORK, TECHNICAL TRAINING, and VOICE. The categories were repeatedly questioned, grouped, and compared for similarities and differences, which were used to further define the concepts and their interactions with each other. The process of identifying relationships, axial coding, begins once the initial categories have been identified.

The first six interviews were coded repeatedly for activities that related to initial descriptive terms in order to abstract the descriptive information. The activities were eventually expressed as a gerund followed by a noun. From interviews with the participant/directors, the following abstracted codes emerged, presented along with their frequency: AWARDED CONTRIBUTIONS (6), BECOMING A DIRECTOR (16), BECOMING A SELF-ADVOCATE (8), BEING A FRIEND (5), EXPLAINING THE

PROJECT (4), LEARNING METHODS (9), PARTICIPATING IN THE GROUP (7), REMEMBERING INSTITUTIONALIZATION (3), SHOWING VIDEOS OUTSIDE THE GROUP (12), and TELLING STORIES (9). Coding categories that emerged from interviews with the participant/liason were: BECOMING A SELF-ADVOCATE (2), COLLABORATING ON PROJECT (6), CONTRIBUTING TO COMMUNITY (9), LEARNING METHODS (18), PARTICIPATING IN THE GROUP (16), PARTICIPATING AS HOST ORGANIZATION (1), REDEFINING CITIZENSHIP (6), REMEMBERING INSTITUTIONALIZATION (9), SHOWING VIDEOS OUTSIDE GROUP (5), and TELLING STORIES (3).

Based on the initial interviews with self-advocate directors, the most common category was BECOMING A DIRECTOR. Under which circumstances did someone become a director during the two years *this ability media club* met at BACI? If someone became a director by attending the *club*, what were the dimensions and possible outcomes of that experience? Based on the categories grounded in data, the director was PARTICIPATING IN THE GROUP, EXPLAINING THE GROUP TO OTHERS, while SHOWING VIDEOS OUTSIDE THE GROUP. The directors might be TELLING THEIR STORIES OR ENCOURAGING OTHERS TO TELL THEIR STORIES. Some of the messages contained within the stories are the acts of REMEMBERING INSTITUTIONALIZATION, BECOMING A SELF-ADVOCATE, and self-sufficiency based on EMPLOYMENT. A more complete examination of the categories and their dimensions takes place in Chapter 4.

### **3.2.3 Identifying the central category**

Within the study of *this ability media club*, the research approach to re-interviewing shifted from identification and frequency to expansion of the central

category, BECOMING A DIRECTOR, and sub-categories such as CONTRIBUTING TO COMMUNITY and REDEFINING CITIZENSHIP. Although the central concept can only be applied to the directors, the interactions of others within the situation are analysed in relation to the activity of voice creation by the directors. Part of becoming a director is telling a story from a particular perspective, finding one's voice in order to communicate with others.

In the initial round of coding and comparing data utilizing the Strauss and Corbin (1998) methodology, the first three interviews with participant/directors were compared with the first three interviews with the participant/liaison. Subsequently, the planning document that led to the formation of *this ability* was compared with two interviews with a BACI administrator and to the previous data set. The third set of data compared field notes of the instructor and liaison to previously coded data. Additional interviews with participants from all levels were guided by the necessity to theoretically sample further data in order to expand previous interpretations. Beginning with a micro-analytic approach to coding and writing memos to analyze the data, the mapping of relationships also took shape within a visual conditional matrix. As each layer of information was added, the categories achieved greater definition based on examining multiple viewpoints of the situation. From the other two levels of interaction, LEARNING METHODS emerged as a dominant coding category for the middle liaison/instructor level and EXPLORING PHILIA DIALOGUE at the administration/public policy level. As Strauss and Corbin (1998) state when discussing the central category:

A place to begin is with the central category itself. A central category, like any category, must be defined in terms of its

properties and dimensions... To check for consistency and logical development, the analyst can stand back and ask himself or herself (because by now the analyst is so immersed in the data) what he or she thinks the properties are and then go back and see how much of this has been built into the scheme... Sometimes, it is simply that the analyst is almost there but, without realizing it, has taken the wrong stance toward the data; that is, it is easy to look at the data from the perspective of the analyst and not the respondents while thinking that he or she is doing just the opposite (p. 157)

After comparative coding and writing memos resulted in the initial identification of categories (including the central) and their interactions, the process of integrating the coded data into a unified theory began. Two techniques described by Strauss and Corbin were useful in developing the current analysis. Writing an analytic storyline helped to narrow the list of categories by hierarchy and resembles a filmmaker's self-promotional elevator pitch. Through composing the storyline, the researcher attempts to answer questions such as: What is the research about and how can these insights be applied in similar situations? Using the conditional / consequential matrix (see Figure 1, p. 12), the storyline of *this ability media club* might be that the participants joined the group in order to learn media skills. As time went on, the participants refined the stories that they wanted to tell and become directors when they decided to tell the story using digital video. Using the matrix as an illustration, the story of the *media club* was re-told to the participants, who were invited to add more detail to the storyline.

The other technique involves creating a visual representation of the research, the conditional/consequential matrix (see Figure 1, p. 12). Through mapping of a central category – a category whose position is most inclusive of

the other positions – within the matrix, actions and relationships can be extended. In Strauss and Corbin's second edition of the Basics, the conditional/consequential matrix is defined as: "An analytic device to stimulate analysts' thinking about the relationships between macro and micro conditions/consequences both to each other and to process" (1998, p. 181). The individual is placed at the centre of the matrix, and relationships are mapped from micro to macro, while recognizing that actions move both inward and out. As Strauss and Corbin state: [italics in original text] "*Action/interaction is not confined to individuals per se; rather it can be carried out by nations, organizations, and social worlds, albeit by the individuals within these who are representing the nations, organizations, and social worlds*" (1998, p. 187).

While BECOMING A DIRECTOR is the central theme for the participant/directors, it is not the central theme for the liaison, instructor, or the organizations. Only the participant/directors became directors through participating in *this ability media club*; the others, while supporting the directors' efforts, were motivated by other objectives within the situation. Rather than conducting a classic grounded theory study of many types of novice directors in order to learn more about their experiences, this study seeks to compare the actions of different players within one community-based media project, in order to examine the interplay between a variety of interests. While the classical grounded theory methods of Strauss and Corbin work well within the levels to compare similar experiences, they fall short of capturing the whole picture. In order to examine a variety of perspectives in more depth, after the matrix

technique was applied I turned to Clarke's (2005) situational analysis techniques to extend the concepts.

Clarke (2005) has incorporated situational and discourse analysis into classic grounded theory so that the analyst can use to further interrogate the data and relationships between the categories. She states that they...

...provide new means of entering and mapping data, situating individuals and collectivities, nonhuman actants, discourses, organizations, and so on. They offer new modes of interrogating data analytically, demanding careful consideration and considerable reflexivity on the part of the researcher. They can supplement and complement "basic social processes" analyses generated through traditional grounded theory (2005, p. 140-141).

Reflecting on the data is part of the grounded theory approach, which consists of simultaneously gathering and integrating data into a framework of categories. As Strauss and Corbin (1998) have written:

One does not stop coding for properties and dimensions while one is developing relationships between concepts...Both dimensions and relationships add density and explanatory power to a theory and will continue to emerge during analysis...A category is considered *saturated* when no new information seems to emerge during coding, that is, when no new properties, dimensions, conditions, actions/interactions, or consequences are seen in the data. However, this statement is a matter of degree (p. 136).

Clarke (2005) applies the concept of saturation to her positional maps, which "lay out most of the major positions *taken in the data* on major discursive issues therein—topics of focus, concern, and often but not always contestation" (p. 126). The positional map is complete when it is saturated – "Here, saturation means that no hot new issues, axes, or major positions are popping up in new data" (Clarke, 2005, p. 135-136). After repeated interviews with individuals

involved with *this ability media club*, the categories that developed out of the data have been saturated to the point where the next step would be to compare the experiences of this group to another community-based media project in an empirical setting.



## CHAPTER 4: POLYPHONIC POSITIONING

From February 2005 to March 2007, the Burnaby Association for Community Inclusion (BACI) hosted a weekly 90-minute media workshop for its members, especially those with developmental disabilities. Six members of the group directed their own video productions, in partnership with the National Film Board of Canada (NFB). Within this chapter, a discussion of agency, self-expression, and collective intelligence are presented in relation to categories that emerged from three levels of interaction. As a result of participating in *this ability media club*, the community-based directors demonstrated agency by creating media works that expressed a unique viewpoint by telling a story. Through providing leadership, support staff, and fundraising, BACI and the NFB were able to articulate their organizational mandates by facilitating the creation of the videos. While the Philia Dialogue does not explicitly mention the contribution of media productions, a comment from an administrator summarizes the situation: “Storytelling is about contribution and celebration and...we all have stories to share” (Administration/ public policy respondent CH2)

Although agency plays a role within all levels of interaction, the activity is combined with self-expression for the participant/directors – they were the only participants who contributed to the project through telling their story. The middle level, consisting of the instructor and the liaison, acted to support the directors

and to carry out the stated objectives of the organizational partners. The viewpoints of the various participants in *this ability media club* are analysed below in relation to specific coded categories, their multiple voices combined in a polyphonic chorus of positions.

## 4.1 Participant/directors

### 4.1.1 Becoming a director and authorial agency

**Interviewer:** Now pretend that one of your friends wants to join the media club. Or they are thinking about it. What would you say to them to convince them to come to the media workshop?

**Participant/director TG1:** They have to take some steps, how to become a director of their own. And need some help, to describe how it works, how to become a director. It's like me, I was doing, interfering with my dad, something like that, give them some tips, and give them some guidance...

Within this project, the process of self-advocates becoming directors emerged as the central activity, one that involved the support of other individuals and organizations. Interview collection and data coding began with the self-advocate directors, using categories that emerged from their data to frame an analysis of the subsequent interviews. As a result, the initial coding and emphasis in this study is based on my interpretation of the data representing the perspective of the self-advocate directors. Other interview respondents and organizational sources of data were chosen to represent a more macro perspective, expressing participation as a result of supporting the efforts of the self-advocates to become directors. Although the program itself could not have taken place without administrative support, this level of invisible organization was

not recognized in interviews with the directors. From the directors' perspective, it was not necessary to ensure that funding was secured or that organizational partnerships were defined.

Once the directors had developed the technical skills, and mentorship was in place, their ability to express agency by telling a story was the most significant step toward making a video of their own. Based on the experiences of the directors since making their videos, authority increases when a person changes from being silent or unheard to being someone with something important to say. The respondent who was previously quoted drew attention to the transition that occurred while he was filming his father. As a director, he gave guidance to his father (the interview subject in his video) – someone who had previously been in the sole position of authority.

Authority is a characteristic of BEING A DIRECTOR and was expressed by the participant/directors since they had the final say in the content and presentation of their videos. Although copyright was assigned to an organization and not to the individual directors, this assignment does not remove or negate authorial agency. The intention of the organizational partners was to empower the directors by creating an opportunity for them to express their social value through contribution. In practice, the position of the administration is that the directors always give approval before their short films are shown. For every public screening, permission is sought from the directors. However, once a director gave permission for online distribution, the film was uploaded until or if consent was withdrawn. Of equal or greater significance from the self-advocates'

perspective is the higher social status of BECOMING A DIRECTOR, someone who has authored a publicly available media work with high production values. As an administrator observed...

**Administration/public policy CH1:** To me, that's one of the most powerful things, actually about *this ability* is the credits that the folks get in terms of making the movie. You know, they're not just the subject of the movie. They are the director. They chose music. They did help editing. They helped with the sound. You know, they helped with all of the key decisions related to those films.

The participant/directors assign numerous qualities to the category of director that contradict the dramatic Hollywood version of the role. From the self-advocates' perspective, the director asks questions, speaks to the camera, tells a story, encourages others to tell their story, is interviewed, and is rewarded in an Oscar-like award ceremony. Most of these qualities are associated with self-expression and the development of leadership skills by self-advocates, as their training revolved around preparing personal documentaries. In a dramatic production, the director would not be asking questions or doing interviews, although the narrative work would also tell a story. Since the Hollywood director model is the form that most are acquainted with, the Oscars that the directors received at BACI were indicative of the parallel achievements of better-known colleagues. Just like Hollywood directors, the participant/directors walked down the red carpet and, after accepting the award, gave speeches in which they thanked their parents and crew.

**Interviewer:** And have you ever been part of making a video before?

**Participant/director GG1:** Long time ago, I did a real movie...It was part of Burnaby Association. And it was actually; I wanted to tell you what it was. It was actually, the *Behind the Mask* movie with Donald Sutherland (Brooks, Morrow, Heus & McLoughlin, 1999).

**Interviewer:** Oh. And what part were you in there? Were you an extra?

**Participant/director GG1:** Yeah I was an extra. I got involved in it from Burnaby Association.

Prior to joining *this ability media club*, none of the participant/directors had experienced playing the role of a video director. Two of the participants had been extras for Hollywood movies, what the respondent above refers to as “real movies.” After acting in live theatre, two had auditioned for mainstream dramatic movie roles to play a character with Downs Syndrome. Taught to direct documentary productions, the group members became directors slowly over a period of time. Agency expressed as initiative played a role in the filming process, since the directors who were sufficiently able to articulate their story and organize their time were those who began and completed their films. The majority of participant/directors told one aspect of their own personal story. However, one told the story of his relationship with his father. Another shone the light on the process of becoming a self-advocate through a documentation of his interview subject’s response to past institutional abuse.

When asked to describe what happened at the group, one participant stated that he was learning to become a director and another discussed the technical skills she had learned. Participating in the group and acquiring technical skills were part of becoming a director, but the role also involved social

engagement and critical discourse. The learning process for each director included the opportunity to screen raw footage for the group, inviting feedback and suggestions.

Directors kept a folder containing paperwork associated with the project, including notes about the screenings written on personalized letterhead. A title at the top of the otherwise blank page read “This Ability Media Project” (originally the name of the group). At the bottom of the page in the footer area, a small digital image of the participant was to the left of the title Director: followed by the participant’s name. In addition to being a place for note-taking during screenings, the letterhead also reminded participants of their new role as directors.

The “feedback loop”, described by Smith (2004) as part of the *Challenge for Change* legacy, allowed Fogo Islanders to respond to unedited footage of other islanders without intervention by the outside organizations involved. *Photovoice* uses a similar process, encouraging participants to screen and discuss their images within the group before public exhibition. Critical discourse undertaken by *this ability* members was crucial to becoming directors. Warschauer’s citation of Freire and Macedo is relevant: electronic literacy “entails not only the individual activity of reading the *word* but also reading the *world* and, in a sense, writing and rewriting the world” (Warschauer, 2003, p. 118).

Describing the group to a friend who wanted to join, a third participant/ director spoke of inviting someone he’d met at a workshop. The gathering was attended by 30 to 40 self-advocates, and took place in the context of a larger “community living” provincial conference. Two participant/ directors from *this*

*ability media club* showed their short videos, and encouraged other self-advocates to tell their stories in writing and by speaking at the open microphone. This is the way that the director described how someone could join...

**Participant/director AZ1:** ...I would tell them when we meet. First thing is, do you have hours personally and what kind of thing would you like to do and if they understand where I am coming from then, well I would just say..."Remember what you said to me when I put that workshop on," And oh, he'll say, "Oh yeah" and then I'll ask him, "How does he feel? Do you feel comfortable or do you want someone else to do the interview? Or if you want me to do it with you, I'll be glad to do the interview with you, with that. Because I already know you." And so, the person will say, "OK great." And then, I'll introduce him to [participant/liaison] and you [participant/instructor]...

Because the project was oriented toward documentary production, AZ advised his friend to become the subject of an interview. Would the friend be comfortable with AZ asking the questions? If his friend agrees, it is possible for them to work together in the group. The process of joining the group was made easier by having a friend who already participated, and who could introduce the potential member to the liaison who represented the host organization and the instructor, who represented the media organization. Within the situation of *this ability media club*, joining the group is the first step toward becoming a director. In addition to the work done at BACI at the weekly meetings, the process of becoming a director takes place outside the group when the videos are shown to an external audience and when the directors share media skills with others in their community.

#### 4.1.2 Showing videos outside the group and contributing to community

**Participant/director AZ1:** ...when I get interviewed on camera, like when we had the Shadbolt Centre recently...and we had people from the audience, too, because I would like audience people to get involved with it. Maybe we can go to another place and they might want us to do that and I like some audience people to come out and hear about us more. Because we are such a big area in Burnaby, you know if somebody hears more and asks us to do this and if it's a television appearance or whatever, you know, all that if it works.

In this excerpt from the transcript, the director discusses another event in which *this ability* videos were shown – the celebration at a local community centre which took place as part of the 50<sup>th</sup> Anniversary of BACI's founding. To begin the workshop process, the directors introduced their videos, screened them, and answered questions afterwards. Prior to the workshop, members of the *media club* practiced their opening speeches, and developed ideas that they intended to share. After the director's presentation, participants from the audience were asked to write a statement or story about what community meant to them. Then *this ability media club* directors worked as a team, one interviewing the audience members while the other recorded the footage.

In a discussion of the NFB's *Challenge for Change*, Rennie (2006) states: "community broadcasting did develop in Canada, and it is now seen by many as the birthplace of the community broadcasting movement in the First World" (p. 48). Rennie (2006) notes that the role of filmmaker was in transition because of the NFB program.

The idea that the filmmaker could, through the use of technology, shape social relations in ways different from predominant mass media formats became the first justification for community broadcasting and cablecasting. At its heart was the concept of



access—access to distribution of community-produced programs via broadcast or cable technology (p. 47).

The production environment of *this ability media club* and early community cablecasting were modelled on *Challenge for Change*, a process that involved participatory support by a filmmaker or trained technicians who were willing to be guided by the community. In all three situations, the community members were learning to use the technology at the same time as learning to use film/video as a vehicle for communication. As a result of novice directors from a marginalized community discussing and demonstrating the experience of self-expression, audience members themselves were invited to cross over and to temporarily become directors, either immediately as in the case of *this ability's* participatory workshops or through joining a community cable station. The novice directors not only screened their own work but encouraged others to share their stories publicly. In both examples involving public participatory workshops discussed above, *this ability* directors asked questions to the audience and recorded the response. These actions echo the ideals of Rodriguez' notion of citizens' media, where participants and communities are reshaping themselves through the representations they have constructed. Through the participatory workshops, the directors become interrogators on behalf of their community. They encouraged others to recognize and utilize their voice in order to express themselves on the subject of social inclusion of people with disabilities within various geographic and social communities.

Although not immediately related to the Internet, *Challenge for Change*, *this ability media club*, and *community cable* contribute a perspective not

commonly found in commercial broadcast networks. As more community-based programs migrate to Internet distribution, their contribution to collective intelligence will grow. Instead of cablecasting, the short films created by *this ability* media club members were uploaded to the NFB's CitizenShift (see: <http://citizen.nfb.ca/onf/info?did=1581>) in April, 2006 and to YouTube in June 2007 (see: <http://youtube.com/user/BurnabyAssociation>). As Lévy (1996) has written, collective intelligence is "a form of *universally distributed intelligence*, constantly enhanced, coordinated in real time, and resulting in the effective mobilization of skills", but adds: "The basis and goal of collective intelligence is the mutual recognition and enrichment of individuals rather than the cult of fetishized or hypostatized communities" (p. 13).

Internet distribution is only one aspect within the situation of *this ability media club*. At public appearances and screenings involving participant/directors, ideas about the contributions of people with developmental disabilities have been extended beyond BACI into an audience from the wider community. Although the concept of citizenship is open to interpretation, the leadership of self-advocates within the discussion enabled the audience to focus on contributions and the unique abilities of all community members. From the perspective of the participant/directors, Internet access to their videos was mentioned in terms of frustration at difficulty in accessing the CitizenShift site. When the dossier was featured on the site, there were up to 3,000 visitors daily, according to a staff member. While YouTube does not promote individual videos

in the same way as CitizenShift, its distribution is much wider and site features allow the numbers of visitors to each video to be compiled.

One of the participant/directors described himself as an ambassador on behalf of BACI and self-advocates. Based on his social sensitivity, as well as his media skills, he was invited to become a leader for another media project involving self-advocates. The purpose of the workshop was to encourage self-advocates to learn to express themselves to those in positions of authority, such as a support worker, the staff in a group home, or even a family member. The workshop is based on the belief that if self-advocates are supported to take small steps, like practicing assertion and recording their efforts on video, they will eventually be able to take the larger step of advocating on their own behalf.

When members of *this ability media club* introduce and screen their videos, an audience might see them as representatives for their community. Two of the participant/directors have begun to introduce and screen the videos on the first day of a program for new BACI staff.

**Administration/public policy CH1:** With *this ability*, GG and AZ are part of our staff orientation, showing *this ability*. You know, so they've taken on a greater role in terms of leadership in the organization, even from a systematic perspective, right. They're welcoming our new employees and orientating and showing them the power of *this ability* in their films. Right. What they have to say.

Community is not static; people experience a heightened sense of connection in situations like the participatory workshop but also through online interaction in sites like Facebook, Flickr, or YouTube. As Kramsch et al. have stated: "The powerful appeal of the computer is due to its promise of granting

agency and a stronger sense of identity to its users because of its different space and time scales, its easy intertextuality, and its speed of access” (2000, p. 98). They have also noted that learners express their voice through multimodal texts. By sharing similar interests and perspectives people were brought together as a community but the grouping was temporary.

It is important to remember the power of personal contact in the age of collective online intelligence. As many of the BACI staff members were new to the field, their contact with someone with a developmental disability who has become a video director would have been limited. Instead of being individuals who are in need of care, the self-advocate directors have demonstrated their abilities, expressed when they were provided with adequate support services and accessible equipment. Instead of being clients, the self-advocates have become people capable of making a unique contribution. At the same time, it must be recognized that people with developmental disabilities encounter social barriers to full access and participation that must be addressed by the larger society.

## **4.2 Participant/liaison**

The participant/liaison was employed by BACI the host organization, was part of the committee that hired the participant/instructor, and has had many years of experience engaging with people with disabilities. Since the group began, she attended most meetings and took notes during the media instructional workshops. During the video production phase of the projects, she collected signed permission slips for those who appeared on camera, locations in which recording took place, and for any works of art that appeared within the

picture frame. She also coordinated rides, asked permission in advance for filming, and helped the directors to organize their production schedules.

Based on the codes generated from the initial three interviews, it is possible to note that the liaison was not BECOMING A DIRECTOR, an activity that was only undertaken by the participant/directors. Instead, she was PARTICIPATING IN THE GROUP, helping to promote LEARNING METHODS and COLLABORATING ON A PROJECT that was CONTRIBUTING TO THE COMMUNITY through REDEFINING CITIZENSHIP and REMEMBERING INSTITUTIONALIZATION. She ensured that directors were aware of opportunities for SHOWING THE VIDEOS OUTSIDE THE GROUP and also ensured there was a chance to communicate for anyone who wanted to be TELLING THEIR STORIES.

#### **4.2.1 Contributing to community through participating in the group**

Through participating in the group, the participant/liaison gained a deeper personal connection with group members, observing that the *media club* was something that they experienced together, rather than just being a training program.

**Participant/liaison OF2:** ...I went through a process with the individuals. We have a different kind of relationship, and that will always be there, that will never go away and you know, we went through this together, you know and I learned so much about them.

Describing conditions associated with collective intelligence, Lévy writes:

“In addition to the required technical instrumentation, the project for a knowledge space will lead to a re-creation of the social bond based on reciprocal apprenticeship, shared skills, imagination, and collective intelligence” (1996,

p.10). The experience of creating a knowledge space brought not just the directors, but all members of *this ability media club* closer together. Beyond gaining a deeper connection with the community of self-advocates, the liaison observed that the project enacted the principles of one of the sponsoring organizations, *Philia – A Dialogue on Caring Citizenship*.

**Participant/Liaison OF1:** I think it became, it was a natural part of people, hospitality, reciprocity. It was kind of a natural part of citizenship. And what the whole project was about, about furthering the knowledge in community about people with disabilities and their contributions and that's all that *Philia* is about, enlisting more of the community to understand the contributions of people with disabilities. And really, what citizenship is, and again, taking it beyond the traditional definition of citizenship, to citizenship as a sense of belonging and contribution. So I think that's why *Philia* was getting involved.

Although *Philia Dialogue* principles were crucial in understanding the contributions of people with disabilities, it was through the creation of a community of practice involving media practitioners that allowed participants to become directors. In her interviews, the participant/liaison OF discussed her role within the *media club*. At first, she felt outside the group, that she had nothing to contribute since her knowledge of the media process was limited.

Simultaneously, she felt like an inside member of BACI who was showing the new instructor around, performing introductions. She acknowledged that over time, she became a participant in the group by learning video production skills along with everyone else. Her participation became her contribution, and the act extended to include a greater understanding of citizenship.

**Participant/Liaison OF1:** But I think, to be a citizen, you need to feel that you belong, to your community or you need to feel that

you're contributing, worthwhile. And that is citizenship. I think my definition of citizenship has changed, EM, I think I have come to a greater understanding of what citizenship is and really being a citizen and contributing to your community.

Rather than becoming a creator of content or a director, the liaison's assignment was to be receptive to the directors' comments and concerns. Lévy (1996) notes that part of building an intelligent city is by listening: "post-media modes of communication are capable of restoring the diversity that arises from effective practice. Listening consists in making visible or audible, in coaxing forth the ideas, arguments, facts, evaluations, inventions, and relations used to weave a social reality..." (p. 70). By engaging with the self-advocate directors through being present and listening, the liaison participated in the process of expression. "Listening reverses the direction of the media. It amplifies the many-voiced murmur of the community rather than serving as a conduit for its representative" (Lévy, 1996, p. 71).

As a result of her involvement in *this ability media club*, the liaison was assigned to be the liaison for another community-based media project. A program for youth with disabilities, *open i* generated a number of short dramatic videos. The media works were written by the participants, who also directed, shot, and acted in the shows. After working with the adult program who developed documentary skills and the youth who worked in drama, OF was in a position to compare approaches of the two programs. They were similar in that the ideas and artistic direction came from the participants, who worked in workshops and through mentors to make short digital video productions.

**Participant/Liaison OF3:** So I think that process in the very beginning was the same but the outcomes were a little bit different in the way, in the way that the youth had a message that they wanted to get across about being bullied. And that was their message that they wanted to get across and that's what they speak to, collectively...it was all staged down to what each person was going to say, word by word. Whereas, with the one that we did...it was...what they meant to say in it, but it was not staged, it was, it was true conversation that came from within, it was not staged, we didn't practice it ahead of time.

As the liaison noted, the directors chose participant-centred content as subject matter for both the dramatic production and the documentary community-based projects. Although the narrative approach began with community dialogue, the process migrated to a fixed script, which led to repetitious actions and dialogue. To the liaison, the documentary approach of *this ability* seemed to be more spontaneous. As Lynn McKnight, a member of the Center for Documentary Studies at Duke University wrote:

Using the products of documentary work in strategic ways, particularly through facilitated discussion with public audiences, extends the notion of connecting documentary collaboration and community goals through the final stages of the documentary process, beyond passive presentation to active engagement of community members in responding to the content of the work. When residents view local concerns through the long lens of a documentary perspective, cultivated over time, they are likely to discover new opportunities for dialogue and develop new visions for the future of their shared surroundings (2003, para. 36).

Similar to *this ability*, community-based theatre productions use drama and narrative structure to engage audiences in a subsequent dialogue as well as to entertain them. Discussions with the audience may occur, in much the same way that *this ability media club* members encouraged the audience to give them feedback. The role of the liaison began as a listener, and through a process of



reciprocity became an advocate for community dialogue. She encouraged the participants to act as agents, first by learning to be directors inside the group and later by encouraging others to tell their stories. Through participating in the process, both the liaison and the directors achieved a greater understanding of the other's position, contributing both to citizenship and collective intelligence.

### 4.3 Participant/instructor

**Participant/instructor:** I didn't realize that the individuals who are part of BACI, the self-advocates, that they have to prove themselves before they are allowed to take a bus by themselves, or allowed to do various things. I remember [CH, host organization administrator] was commenting on this, that it was really a different model we were trying to use in the *media club*, where we're encouraging everyone to do it and to see if they can do it, and to let them try doing it, before they had any kind of approval...

**Participant/liason:** ...I think the media group, if it had taken the first way that you had talked about, about learning it first, I don't think it would have been as magnificent as it was in the end. I think the way they went about it, looking at it from a very grassroots organic way that it flowed was [the] best way, I think, for all of us. For me too. I struggled because we had no direction, we had no, nothing, and it was so hard. But I think the *media group* was more at ease with that, like they took the learning and just went with the flow in whatever we were doing.

Within the infrastructure of interaction surrounding *this ability media club*, participants learned to become directors through regular instruction in media skills, hands-on access to digital video equipment and editing software, and sustained logistical support. Employed by the National Film Board of Canada (NFB), I played the role of participant/instructor. Based on my years of experience as a documentary director, I have taught a wide variety of learners. Previously, I worked with self-advocates on a video about the community-based

visual art project *From the Inside/Out!* (BCACL & Boschman, 2000). The award-winning documentary examines a visual art show by self-advocates who told of their younger years spent living inside large institutional settings like the Woodlands School. *This ability media club* began as an open project that found a concrete form when participants were asked to direct their own production.

#### **4.3.1 Learning and teaching process**

The original NFB vision of *this ability* was patterned on the democratic media experiments of *Challenge for Change*. In a report to their head office, NFB producer Tracey Friesen described *this ability* as “an entirely process-oriented project, with no clear and pre-determined outcomes” (2005, p. 13). My initial strategy as *this ability* program director was to get to know the self-advocates, bring in the equipment, and facilitate the recording of previously “silenced” voices. I imagined that while the adults with developmental disabilities gave voice to their concerns, others would practice their camera skills and record them. In the original metaphor for the group, the liaison and I described it as a form of Speakers’ Corner, a way for self-advocates to speak to each other and to their surrounding community. Originally, in addition to video activities, the group also included scrapbooking, a visual art form that combines still images and text collaged onto a page. Footage shot by *media club* members was screened for other BACI members in the cafeteria area, although the practice did not lead to the level of community discourse or feedback loop described by *Challenge for Change* participants.

In the first few months, group members were invited to record several community functions. Since the equipment was not available without supervision outside of the weekly class, these events gave participants an opportunity to practice camera skills. As one of the participants commented, if the equipment was not always available, they would have to learn from each other. In comparison to other students I've worked with, the self-advocates lost interest very quickly in theoretical discussions. Rather than explaining all of the rules before they went behind the camera, I often waited until the material was presented to the class to explain the need for technical improvement. Hearing that the sound was quiet reinforced the relationship between the recording and the playback levels. Seeing images that weren't lit well and talking about how to improve the video visually was more effective than trying to explain lighting beforehand. Although this method could be referred to as "learning from one's mistakes" that language choice was inappropriate. When footage was screened during the class, I mentioned that something was a mistake, prompting one learner to bang her head on the table. Subsequently, there were no "mistakes" in the *media club*, only opportunities to make something even better technically.

According to Warschauer (2003), in many countries including the US, the two dominant viewpoints on education are the transmission and constructivist processes. In the first, rote materials are communicated from instructor to learner regardless of the relevance of those facts in today's society. Alternatively, constructivists encourage exploration on the part of learners and include social interaction as part of their pedagogy. As Warschauer notes, neither approach

completely addresses the most common way that people learn how to do things  
– through communities of practice.

An excellent example of this is found in writing. One learns to write not by memorizing facts about writing but by engaging in the social practice of writing in the company of colleagues, peers, critics, and mentors. Learning how to write involves appropriating the language of others, reproducing examples of writing that one reads, responding to questions and suggestions, and receiving and considering the guidance of expert critics—a classroom teacher, a dissertation committee, or the peer reviewers for an academic journal. Learning *about* writing might take place in a few days by reading a book; learning *how* to write takes years of engagement in communities of writers (2003, p. 122).

Applying this principle to the group, their community of practice for video making was through *this ability media club*. Although some learning took place formally when visitors or I led workshops, much more took place informally by observing and imitating others. After four months of media training, the participants had learned the basics of setting up digital video production equipment for use with available lighting. When two new members joined the group, the experienced members were able to demonstrate tasks like putting the battery onto the camera, putting the camera on a tripod, and connecting the camera to a television so that the whole group was able view the image. As often as possible, the image from the camera was available for the whole group to watch. For over a year, the NFB supplied professional video equipment to the project and made duplicate copies from the original digital video tapes for the group members to view and discuss critically.

During the first few months of *this ability media club*, the participants worked as a group, trying to articulate areas of interest or concern among BACI

members. Based on advice from the Advisory Committee, we initially emphasized recording interactions with self-advocates who communicate non-verbally, in order to show their contribution to the community. However, this strategy did not encourage the development of individual self-advocate directors and would probably have required me to act as director because I was the only participant with directing experience. As a result, during the first summer of *this ability*, the NFB producers and I began to more actively encourage each self-advocate participant to make their own video, rather than trying to create a group work about citizenship, community, and belonging.

The decision to encourage individuals to become directors was based on meetings with the Advisory Committee, a group comprised of representatives from BACI, the NFB, Philia, parents/caregivers of the participants, and the self-advocate directors. Following an invitation to tell their own stories based on their contributions to community, participants began to create the media works that would eventually demonstrate that they had become directors. The turning point in self-expression came as a result of leaving behind a poorly defined but ideologically sophisticated group project and embarking on individual videos that incorporated their own vision. Through tapping into individual agency, instructing the directors became a way to support wider social development by developing leadership skills among the participants. The steps of creating a video production were familiar to both the NFB and to myself as mentor, and these steps provided the scaffolding for participants who in a sense joined our community of practice by directing their own video productions.

Based on advice from the self-advocate participants, the process of video production was broken down into small steps that were easy to accomplish. If one step proved difficult, the participants asked the group and mentor for advice and support. The learner could master each step in turn, knowing that by accomplishing this, a goal could be achieved. The participant/liaison suggested that becoming a director was a process that the participants had to go through.

**Participant/liaison OF4:** But I think how everything else sort of happened organically. I think them becoming a director happened organically as well maybe if ...the outcome of the project was set at the beginning – you will be a director at the end – maybe it would have been different...it's a definition of themselves that they had to grow into...in order to define yourself as something like that, you need to participate in the process.

The process of mentorship and personal training involved working with each participant to develop an individual story. During several workshops with Tracey Friesen, the NFB producer, participants were asked to consider the audience for their video and to think about what would make the video interesting to people from outside their community. After the directors had begun shooting and editing their footage with the assistance of the liaison and I, Tracey returned to give suggestions that would clarify the overall message. An NFB cinematographer/editor also gave feedback to group members, demonstrating another perspective and showing the directors the process of refining video productions before their exhibition. Through supporting the development of agency in the self-advocates and creating an accessible program of instruction based on current documentary video practice, I as the participant/instructor helped shape an environment that nurtured increased leadership skills in

participants. The self-advocate directors went from making their own videos to speaking in public and inviting members of an audience to use the same tools. By encouraging others to tell their stories and express agency through making a video, the directors furthered their own sense of self-determination.

## 4.4 Organization/public policy

### 4.4.1 Exploring *Philia Dialogue*

The organizational perspective has influenced all other levels under examination. The NFB's *Challenge for Change* has a continued legacy among community-based media programs, including *this ability*. An additional unique code emerged at the organization/ public policy level based on the data from an interview with the BACI administrator: EXPLORING PHILIA DIALOGUE.

**Organization/ public policy CH1:** Would the self-advocates go around saying "I'm a part of the Philia Dialogue." No... The word Philia is, to be honest with you, it's kind of our word. It's been the organization's word. It's been the organization's catalyst. For the self-advocates, it's community and feeling welcomed and valued. Being safe. You know, being treated well.

In addition to contributing to BACI's organizational transformation, Philia hosted a series of dialogic exchanges in 2005 and continues as an online resource whose roots are in the disability community (Philia, 2005a; Philia, 2005b). The purpose of the conversation is to transform marginalization into inclusion for individuals who have been unable to participate fully in civic life. Based on a fundamental belief that everyone is capable of social contribution, it is also their belief that society will collectively benefit from these contributions. Philia representatives were supporters of *this ability media club* from the

beginning, and contributed time to the project by serving as members of the Advisory Committee. On their website, Philia discusses *this ability* within the context of the organizational transformation of BACI (Philia, 2005c). In the report “Philia at BACI”, a paradigm shift was acknowledged: instead of viewing people with disabilities as disenfranchised clients or consumers in need of social services, self-advocates became individuals who have gifts or contributions to make to a civil society (Orloff, 2005).



## CHAPTER 5: CONCLUDING STATEMENT

Agency is expressed when individuals take action and achieve meaningful results. The agentic experience of self-expression under analysis in this study – constructing stories using digital video production and editing technology – draws upon skills similar to those required for leadership. The directors exercised self-determination by setting goals and working step-by-step to achieve them. Within *this ability media club*, self-advocate directors expressed agency by first developing their own and their community's stories and then by creating their own video based on the material. They created media works that, when shown to people outside the group, contributed to a collective appreciation of the contributions of people with cognitive and developmental disabilities. Through becoming authors of media works, the novice directors have learned to express authority, an effective form of agentic self-expression. They have joined the experts in video production within their own community through their achievement and by encouraging others to tell their stories.

Past discussions of the digital divide have been focussed on access to the Internet and computers, although concerns regarding access to training have long been embedded within the debate. As physical access has become more widespread, the dominant critique has shifted to include more effective training and better usability design. Lévy's notion of collective intelligence has more

recently been replaced by discussions of networked intelligence, a discourse informed by users and design professionals. These arguments should be extended to include access to digital video equipment. Through promoting more widespread access to digital video equipment and video editing software, communication tools can be used by individuals or communities who have not previously had extensive access to them or training in their use. Through greater ease of use, based partially in instruction designed for people with cognitive disabilities, more self-advocates will be able to learn to express agency and authority through telling their stories.

The use of the feedback loop by *Challenge for Change*, the critical discourse that *photovoice* participants engaged in, and screenings of the works-in-progress during *this ability media club* were all vehicles that allowed community members to contribute. The works that were created through these programs represent the communities and individuals that engaged in the process, demonstrating in part the wider recursive effects of culture on society and society on culture. Differences between the approaches are due in part to the different objectives of the programs: community development through discourse, public health mapping of community assets and problems, and the development of self-expression by members of a marginalized community using digital video production and editing software.

This type of community discourse was also an element of the research method that I chose to help me analyse the experiences of participants in *this ability media club*. Grounded theory encourages the analyst to return to interview

subject in order to verify codes and interpretations. This process of analysis allowed me to engage with the interview and written data in a way that moved the materials from a descriptive form to an abstract one. The central area of study – becoming a director – emerged directly from an interview with a self-advocate participant.

Through going beyond the activities of instructor and program director and developing skills as a researcher, I have been able to demonstrate a relationship between agency, self-expression, self-determination and leadership skills. By becoming a researcher, I have stepped outside the audience/artist paradigm for a moment, allowing myself to study the impact of abstract concepts like agency. By abstracting the data and analysis, connections have been made to other communities of practice, as well as to the work of other academic researchers in related fields. Rather than locating this study in relation to the audience, I have shifted to a critical discourse with academic researchers, while still remaining grounded in data based in pragmatic experiences and actions.

Through creating *this ability media club* – a community-based media project – a community of practice was created where people with developmental disabilities were able to learn digital video skills at their own pace and based on their own abilities. The *Philia Dialogue* suggests that citizenship is linked to recognizing the contributions of people with disabilities. By encouraging the social model of disability, a civil society actively supports and encourages participation by all individuals, including those with disabilities. Rodriguez' (2001) concept of citizens' media states that by creating their own media, marginalized

communities enact their citizenship; they contribute to their own social power by creating alternative representations of themselves and their community. As Alhearn (2001) suggests, agency is not an individual trait but is part of a recursive relationship with culture. A culture based on critical discourse is one that encourages multiple positions. By encouraging self-determination and the development of personal and leadership skills through community-based media programs, communities and individuals that have previously been marginalized can practice citizenship through utilizing digital video equipment and editing software.

Growing out of this thesis, my future work will include three considerations: studying qualitative research methods at the intersection of cultural and media studies, developing a research method based on discourse analysis to interpret the content of community-based media works, and continuing to interpret the role of agency in the process of becoming a director through community-based media programs. Because of my background as a media director and community-based instructor, I am in a unique position to examine and interpret the process not only of becoming a director, but how the expression of voice contributes to social inclusion.

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## **APPENDIX 1: RESEARCH PROCEDURES RELATED TO ETHICS AND INFORMED CONSENT**

This research took a particular approach to ethical clearance. Because some of the participants were adults with cognitive disabilities, the standard clearance forms were supplemented by a “plain language” version. The informed consent forms were read and thoroughly discussed during a meeting of *this ability media club*. Following the meeting, potential research participants were encouraged to review the forms with others before signing them.

Form 2 – Informed Consent By Participants In a Research Study, Form 5: Study Information Document, and Plain Language Version of Consent and Information Forms reproduced below are a product of considerable reflection and feedback from experts in social research. Prior to undertaking the research study, the Board of Directors of the host organization, the Burnaby Association for Community Inclusion (BACI) agreed to allow research to take place.

### **SIMON FRASER UNIVERSITY**

#### **Form 2- Informed Consent By Participants In a Research Study**

The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. This research is being conducted under permission of the Simon Fraser Research Ethics Board. The chief concern of the Board is for the health, safety and psychological well-being of research participants.

Should you wish to obtain information about your rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact the Director, Office of Research Ethics by email at [hweinber@sfu.ca](mailto:hweinber@sfu.ca) or phone at 604-268-6593.

Your signature on this form will signify that you have received a document which describes the procedures, whether there are possible risks, and benefits of this research study, that you have received an adequate opportunity to consider the information in the documents describing the study, and that you voluntarily agree to participate in the study.

Any information that is obtained during this study will be kept confidential to the full extent permitted by the law. Knowledge of your identity is not required. You will not be required to write your name or any other identifying information on research materials. Materials will be maintained in a secure location.

**Title:** Constructing voice from within a marginalized community: an analysis of this ability media club

**Investigator Name:** Lorna Rae Boschman

**Investigator Department:** School of Interactive Arts and Technology

Having been asked to participate in the research study named above, I certify that I have read the procedures specified in the Study Information Document describing the study. I understand the procedures to be used in this study and the personal risks to me in taking part in the study as described below:

**Risks to the participant, third parties or society:**

Yes. Emotional or psychological risk to "this ability media club" participants may arise for those who do not wish to participate in the research study but who would still like to participate in the media club. As the director of the media club, I will assure all participants that they are welcome to participate in the club but are under no obligation to participate in the research. Conversations will be recorded only with those who have agreed to be part of the research. Contributions by those who are not part of the research may be recorded as part of audio taping "this ability media club"; however, these verbal exchanges will not be transcribed and will not form part of the written research that is analysed.

**Procedures:**

Participants will be asked to engage in informal short conversations with the researcher. The conversations will be audio recorded for transcription. Questions will be related to the formation and continuation of "this ability media club." Interview subjects will be asked to read the transcripts and may amend materials so that they accurately reflect their viewpoint. Meetings of "this ability media club" will be audio recorded if consent is granted. Activities of the group will be the same regardless of whether research is being conducted, as the research is examining the ordinary activities of the group. Participants are also agreeing to be observed, so that I can write about my observations and use the materials as data for a grounded theory analysis.

**Benefits of study to the development of new knowledge:**

To contribute to the knowledge available to community-based media projects

I understand that I may withdraw my participation at any time. I also understand that I may register any complaint with the Director of the Office of Research Ethics.

Director, Office of Research Ethics  
8888 University Drive  
Simon Fraser University  
Burnaby, British Columbia  
Canada V5A 1S6  
+1 604 291 3447  
email: dore@sfu.ca

I may obtain copies of the results of this study, upon its completion by contacting:

SFU Library - research is for Lorna Boschman's Masters thesis through the SFU School of Interactive Arts and Technology.

I have been informed that the research will be confidential .

I understand that my supervisor or employer may require me to obtain his or her permission prior to my participation in a study of this kind. I understand the risks and contributions of my participation in this study and agree to participate:

The participant and witness shall fill in this area. Please print legibly

Participant Last Name:

Participant First Name:

Participant Contact Information:

Participant Signature:

Witness (if required by the Office of Research Ethics): None required

Date (use format MM/DD/YYYY)

## **SIMON FRASER UNIVERSITY**

### **Form 5: Study Information Document**

Note: Do not complete Form 5 if your study only involves the use of secondary data and there is no requirement to re-contact participants.

This document describes the goals of the study and the procedures to be used including their risks and benefits. If the study is not for the use of secondary data and there is no requirement to re-contact participants, then this document must be completed in the application. This document is referred to in your consent protocol as the information given to the participants before consent is given, to ensure that when the participant's consent is informed consent. Exceptions to the inclusion of a reference to this document in consent protocols may be approved.

**Title:** Constructing voice from within a marginalized community: an analysis of this ability media club

**Investigator Name:** Lorna Rae Boschman

**Investigator Department:** School of Interactive Arts and Technology

**Place:** Canada

#### **Who are the participants (subjects) in this study?**

Adults with developmental disabilities who participate in "this ability media club", project liaison staff, and the co-directors of the Burnaby Association for Community Inclusion (BACI) will be asked to participate.

#### **What will the participants be required to do?**

Participants will be asked to engage in informal short conversations with the researcher. The conversations will be audio recorded for transcription. Questions will be related to the formation and continuation of "this ability media club." Interview subjects will be asked to read the transcripts and may amend materials so that they accurately reflect their viewpoint. Meetings of "this ability media club" will be audio recorded if consent is granted. Activities of the group will be the same regardless of whether research is being conducted, as the research is examining the ordinary activities of the group. Participants are also agreeing to be observed, so that I can write about my observations and use the materials as data for a grounded theory analysis.

#### **How are the participants recruited?**

The co-executive directors of BACI and project liaison staff will be asked to participate. Individuals who attend "this ability media club" will be asked if they wish to participate. If the research extends beyond this group, an additional application will be made for ethical approval.

### **Overall Goals of Study**

My SIAT Masters thesis will contribute to knowledge regarding the construction of voice from within marginalized communities through the use of Information and Communications Technology (ICT) in light of three criteria. My research will focus on sustained involvement by local organization(s), committed engagement of participants, and social contribution to "collective intelligence" through dissemination of the works and research findings. My research addresses the question: "What knowledge has been created by participating in this ability media club that could be incorporated into other community-based media projects?" As the director of a media club for adults with developmental disabilities, I interact with a variety of individuals who have contributed to a local project, including project participants, co-executive directors of a community-based organization and my co-worker.

### **Risks to the participant, third parties or society:**

Yes. Emotional or psychological risk to "this ability media club" participants may arise for those who do not wish to participate in the research study but who would still like to participate in the media club. As the director of the media club, I will assure all participants that they are welcome to participate in the club but are under no obligation to participate in the research. Conversations will be recorded only with those who have agreed to be part of the research. Contributions by those who are not part of the research may be recorded as part of audio taping "this ability media club"; however, these verbal exchanges will not be transcribed and will not form part of the written research that is analysed.

### **Benefits of study to the development of new knowledge:**

To contribute to the knowledge available to community-based media projects

### **How confidentiality and anonymity will be assured if applicable**

Participants will be identified in written materials using random initials. Employees will not be identified by their job title, to protect anonymity. Discussions of media works that have been directed by "this ability media club" members and have been exhibited in public will be discussed separately from the anonymous research data.

### **Approvals that may be required from agencies, communities or employers**

Approval has been forwarded electronically to dore by Tanya Sather, the Co-Executive Director of the Burnaby Association for Community Inclusion.

Statement of Professional Ethics if consent procedure 2b is chosen and any other information or contingencies that may be appropriate

### **Persons and contact information that participants can contact to discuss concerns.**

Dr. Susan Kozel, my graduate supervisor

Email: susan\_kozel@sfu.ca

## Plain Language Version of Consent and Information Forms

Lorna Boschman is part of *this ability media club* and is also a student at Simon Fraser University. I want to learn more about *this ability media club* by asking questions. When I write my report, it is called doing research. I am going to do research so other people who want to have a media club can learn from the way we did things at BACI.

**Who do I want to ask questions to?** People who are part of the *media club* and people who helped the group get started. I will tape the questions and answers and then write them down on paper. Then I will show the paper to the person who answered the questions and make sure they really mean what is written down. You can change what is written down until it is really what you mean to say.

I would also like to tape *this ability media club* every week to help me remember what happened there. I will be writing about what I see happening in the group and why I think it is going on.

When I write down what people said, I will change their name to initials. Why? So that other people can't tell who said what. Sometimes people don't want other people to know their private ideas and that is ok.

**What if you want to come to media club but don't want to be part of doing research?** That is ok with me. What we are doing in the group is just being ourselves and acting like we did before. But I won't write down what you say in the group, if you don't want to be part of the research. What we do in the group and what I write down as part of the research will be different.

**What if you change your mind after you signed the form?** That is ok. You can change your mind anytime, even after you answer questions and I write them down. You have to power to say no if you don't want to be part of the research.

If you have any questions, you can ask Lorna Boschman. Or if you want to complain about Lorna, you can email her supervisor at school, Susan Kozel. Or you can even ask questions or complain to the Director of the Simon Fraser Ethics Board. Their email addresses and phone number are on the other forms.

## APPENDIX 2: *THIS ABILITY* CITATION

The following citation for the documentary based on *this ability media club*, including the six short videos directed by participants, is from the Vancouver Public Library catalogue. The DVD is available in most public libraries.

This ability [videorecording] /written and directed by Lorna Boschman ; producer, Tracey Friesen.

[Montréal] : National Film Board of Canada, c2006.

**Call #:** 362.4 T44b

Subjects This Ability Media Club (Burnaby, B.C.)

Artists with disabilities -- British Columbia -- Burnaby.

People with disabilities -- British Columbia -- Burnaby.

Video recordings for the hearing impaired.

Description:

1 videodisc (ca. 30 min.) : sd., col. ; 4 ¾ in.

Media Note:

DVD-R.

Language:

Closed captioned.

Summary:

This Ability is a filmmaking program for adults with developmental disabilities, formed as a partnership of the National Film Board and the Burnaby Association for Community Inclusion. Over the course of a year, the members of the This Ability Media Club acquired the skills to tell their own stories in their own way. Also included in their entirety are the six short films directed by the self-advocates who participated in the weekly 'Media Club.'

Added Author:

Boschman, Lorna.

National Film Board of Canada.

VPLFormat:

DVD

Contents:

Be kind to spiders / Michelle McDonald -- I love my job! / Shannon Leclair -- Life patterns / Sean Craig -- Community courage / Gerry Juzenas -- Fishing with my father / Watson Moy -- Strengths and weaknesses / Ginger Gibbons.