University of Alberta

Re-vision, Re-right: Challenging Social Perception of Disability with Visual Storytelling

by

Carmen Zoe Norris

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master of Arts

Department of Anthropology

Abstract

This research examines the stories created for Project Citizenship, a collaborative action research project between the SKILLS Society, a non-profit agency that supports people with developmental disabilities, the University of Alberta and the Nina Haggerty Center for Arts. The majority of the stories take the form of short documentary film, each representing an individual supported by SKILLS.

Using photography, survey, participant observation, and interview, this exercise in visual anthropology and qualitative research explores what stories can do and what they can mean for various individuals, namely filmmakers, the subjects of the stories and audience members. A better understanding of how people make sense of these stories in a local context provides insight into the potential visual stories have for challenging social perceptions of disability in our communities and creating a better world inclusive of all its diverse and valued citizens.

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Chapter 1 – Introduction

How does one begin a story? A story about stories? A metonymic, meta-narrative on what stories are, what they can do and what they can mean? There is nothing particularly dark or stormy about this night. Ok it's dark, but the shimmering lights of downtown flickering from across the river are comforting, in Christmas light kind of way. And there's nothing scary or stormy about them really. There is nothing once upon a time-y about this tale either. It is not a fairy tale and it is happening now. Right now. Upon this time, upon this here and now with you and me, together. This is my story. But it is also your story. We are creating it together as you read, for without your eyes, these pages are blank, the contents empty and meaningless.

We are connected you and I, but we are also connected to the people whose tales we shed across these pages like blood and brotherhood. Stories bind us, tether us to each other and all the tales that came before. Through stories we are caught up in a web we call experience, we call human connection, we call life itself. "Stories tell me not only who I am but also who you are, and what we are together. In fact, without you and your story I cannot know myself and my story. No one's story exists alone. Each is tangled up in countless others. Pull a thread in my story and feel the tremor half a world and two millennia away" (Taylor 1996, 6).

Stories are powerful cultural media. They are constructed and given meaning by a group of people who share cultural understandings and perspectives of the world. By investigating how people create, share and interpret stories we can gain rich insights into a society's cultural beliefs, collective ideologies, and shared social values. Keith Basso reveals how stories and storytelling are powerful social and moral tools for the Western Apache community of Cibecue. "Just as 'ágodzaahi [historical] stories are "about" historical events

and their geographical locations, they are also "about" the system of rules and values according to which Apaches expect each other to organize and regulate their lives. In an even more fundamental sense, then, historical tales are "about" what it means to be Western Apache, or to make the point less dramatically, what it is that being an Apache should normally and properly entail" (1996, 52). Stories which at first glance appear to "lack substance or complexity", thorough investigation reveal detailed, deeply nuanced and distinctly Apache ways of being (1996, 41).

For Basso, stories also serve as valuable entry points into people's perspectives and interpretations of the world. In his opinion, studying stories: the way people talk about themselves and the things around them, is a beneficial undertaking. "Attending carefully to the claims that people make about themselves, and then trying to grasp with some exactness what they have claimed and why... can be richly informative and highly worthwhile" (1996, 37-38).

As with stories, examining images can also tell us a great deal about how people view the world. According to visual anthropologist Sarah Pink in her interpretation of Pierre Bourdieu's social theory, "images produced by individual photographers and video makers... inevitably express the shared norms of that individual's society. Thus, Bourdieu argued 'that the most trivial photograph expresses, apart from the explicit intentions of the photographer, the system of schemes of perception, thought and appreciation common to a whole group'" (Bourdieu cited in Pink 2007, 35).

This day and age with the ubiquitous technology of Facebook, Instagram, Tumblr and camera phones, not to mention the obvious media: television and film, it is increasingly clear how images are inseparable from our stories, personal narratives and social identities. Pink recognizes that "images are 'everywhere'. They permeate our academic work, everyday lives,

conversations, our imagination and our dreams. They are inextricably interwoven with our personal identities, narratives, lifestyles, cultures and societies, as well as with definitions of history, space and truth" (2007, 21). Extending the knowledge put forth by scholars investigating stories and academics working with images and visual material, this research is an attempt at exploring the significance stories and images can have for people when they are presented together, woven into tight, unified packages.

Investigating the cultural advancements of stories and images, recent scholarship across disciplines is identifying the potential new technologies such as social media, virtual reality and mobile phones have for assisting people with disabilities (Ginsburg 2013, Manning 2010, Rose 1996, Wade 2001). Unlike decades prior, people with disabilities are able to participate in social activities, share stories, and construct identities in accessible and creative ways. However, many of the prejudices and barriers people with disabilities face in reality, persist in virtual environments largely because the social conditions surrounding disability remain unaddressed.

The social disenfranchisement of disability can be as debilitating as the cognitive and/or physical challenges experienced by people with disabilities. As Emeritus Professor of Disability Studies at the University of Greenwich and disability rights activist Mike Oliver claims,

> disability cannot be abstracted from the social world which produces it, it does not exist outside the social structures in which it is located and independent of the meanings given to it. In other words, disability is socially produced (1992, 101).

Historically, discrimination and negative perceptions of disability have marginalized people with disabilities and inhibited their rights, responsibilities and social inclusion. "In relation to what Allison Carey calls

the "storybook citizen," intellectually fine, physically upstanding, morally both of the above, exuding "intelligence, independence, and the ability to contribute to the national well-being through hard work, political participation, and bravery," people with disabilities have historically appeared "unworthy, at best, and a threat to the nation…at worst". (Carey cited in Schweik 2011, 418-9). Until recently, disability has been storied as clienthood, of people who receive care, require support, and burden society.

Currently, ventures such as Project Citizenship are beginning to address these issues with innovative methods, creating a greater degree of autonomy for people with disabilities and providing opportunities for participation where they can contribute on their own terms. Project Citizenship, a collaborative action research project between the University of Alberta (U of A), Nina Haggerty Center for Arts, and SKILLS society, a non-profit agency that supports people with developmental disabilities and acquired brain injuries, is harnessing the power of stories and images to enable greater inclusion of people with disabilities in regular community life. Its purpose is to generate visual citizenship stories that "provide opportunities for self-expression, raise awareness and possibly initiate social change[1]".

Following a trend in Disability Studies that extends the common definition of 'citizenship 'to encompass farther reaching and more inclusive boundaries, Project Citizenship understands the term to be "much more than: rights + empowerment + inclusion + getting a life. It is a more intangible concept that includes all of these things, but something more. It is the core of what it is to be human" (Hutchinson as cited in Darcy, 2009, p.421). Citizenship, as it is used by the project and subsequently this research, is about belonging, it is about the innate human desire for connection, understanding and respect

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[1] Taken from Project Citizenship's long research description.

that transcends national boundaries, ethnic differences, gender affiliations, and physical or metal abilities.

It is this inclusive, global, vision of citizenship, which the project believes people with disabilities are entitled to. More than addressing inequalities within public policy and institutional services, like employment, migration, housing, transportation, education etc., the project demands a citizenship that is everyday, that is visible in they way people with disabilities are treated in their daily lives, in their routine interactions with people in their local or global communities.

Since the inception of Project Citizenship, September 2011, the project's many collaborators (SKILLS employees, family members, U of A CSL students, community allies, and the individuals SKILLS supports) have been busy creating, documenting and collecting stories. Most of the stories take on predominantly visual forms, yet they range considerably from paintings to short films, comic books, digital stories and photographic collections. Capitalizing on the power of stories and images, Project Citizenship is attempting to confront deeply entrenched cultural beliefs concerning disability. A gallery exhibit and opening night gala event displayed approximately thirty citizenship stories to the public. It ran from September 24 to October 1, 2012 at the Society of Northern Alberta Print-artists (SNAP) gallery in downtown Edmonton.

Beyond creating and sharing citizenship stories for public display, another major aspect of Project Citizenship, called the Action Hall,[2] was developed to bring people together in a collaborative, classroom environment. During the semester people with disabilities, support workers, Community Service Learning students and researchers met once a week to discuss their

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[2] Watch a short video about Project Citizenship's Action Hall online at: http://projectcitizenship.com/u-citizen-action-hall

collective definitions of citizenship, document their dreams and visions for the future and share their stories. At the end of the course each participant was awarded a certificate, but beyond personal achievement the group celebrated the creation of an inclusive sense of community and their collective inspiration to action.

While the Action Hall is another excellent example of how Project Citizenship is fostering community engagement and challenging popular conception of disability, the goal of this research and this thesis is to examine the visual stories made for Project Citizenship to gain an understanding of how stories and images can be used to facilitate the project's goals. Extending the knowledge gathered from a few stories in a local context, this research hopes to provide insight into the potential such stories hold for challenging social perceptions of disability.

Visual anthropologist Gillian Rose claims, "there are three sites at which the meanings of an image are made: at the site(s) of the production of an image, the site of the image itself, and the site(s) where it is seen by various audiences (2007,13). Building upon this frame, I have chosen to examine the stories created for Project Citizenship at these three sites: authors/creators, the people the stories represent, and the readers/viewers who interpret them once they are made and shared. Because the stories on their own contain rich cultural knowledge, some discussion involves an analysis of the stories themselves. Overarching questions include:

1. What can stories in general, and visual stories in particular, contribute an emancipatory project aimed at improving the lives (and public perception) of people with developmental disabilities?
2. What role visual stories do have for society in general?

3. How does the production, dissemination and interpretation of citizenship stories challenge or contribute to existing social perceptions of disability?

4. What issues of representation are at play within these citizenship stories?

<u>Methods and Methodology</u>

To address the questions above, I take a general qualitative research approach. Drawing from ethnography and other research practices in the social sciences (Emerson, Fretz and Shaw 2001, Denzin 2001, Patton 2002, Pink 2007, Rose 2007, and Roulston 2010) I have made use of participant observation, surveys, interviews and visual materials. Outlining these various methods, the following paragraphs reveal the methodological rationale behind how they were designed to address this particular research topic.

- Participant Observation and Fieldnotes

On Sept 24, 2012 I attended Project Citizenship's opening gala as a participant observer, watching audience reactions and speaking with gallery attendees. As Emerson, Fretz and Shaw maintain, "participant observation involves not only gaining access to and immersing oneself in new social worlds, but also producing *written accounts and descriptions* that bring versions of these worlds to others" (2001, 352). Beginning with the gala event, and continuing throughout the research process, I kept a reflexive journal. Following the ethnographic tradition "whereby a participating observer transforms portions of her lived experience into written fieldnotes" I diligently documented and described my research encounters (Emerson 2001, 352).

I found it useful to divide my journal entries into four categories: observational notes (ON), methodological notes (MN), theoretical/analytical notes (TAN) and personal notes (PN). With an emphasis on description, observational notes (ON) guided me to record, in detail, the actives and events that transpired. Methodological notes (MN) directed me to reflect on the research process and adjust methods as required. Theoretical/ Analytical Notes (TAN) began the analytical process. These notes included initial hypothesis, interpretations and critiques of the data. TAN also provide an opportunity for questioning assumptions, reflecting on potential subjectivities, and exploring tensions with the theoretical suppositions underpinning the research.

Lastly, personal notes (PN) allowed me to express my feelings about the research and the participants including my doubts, anxieties, enjoyments and interpretations of what I observed. As Michael Patton affirms, "in qualitative inquiry, the observer's own experiences are part of the data" (2002, 303). Personal notes, thus, kept me connected to the research, personalizing it as my own take on a complex social phenomenon.

- Survey

During the gala event, I handed out a short survey to gallery attendees to solicit their initial thoughts on the event and the stories presented (see Appendix A). To entice people to complete it, I kept it relatively short, asking eight questions in total. I used simple accessible language and prompted participants to provide detailed responses (beyond yes/no answers) by including phrases like "If so, in what ways?" and "Why or why not?".

The first question asked audience members to express their initial thoughts, feelings and reactions to the exhibit in 10 - 25 words. I chose to start the survey with an open question so not to frame the respondent's feedback toward a particular outcome. Limiting the response to 10 - 25 words I gained

brief, but meaningful responses, while leaving the participant with enough energy to fill out the remaining questions.

The remaining survey questions asked for specific information about if/how the stories had influenced audience perception of disability and solicited audience member's opinions on the visual/audio visual medium of the stories. Asking direct questions provided insights into the specific areas I was most interested in. At times, audience interpretation of these questions also revealed nuances and variations I had not expected.

The survey was also used as a recruitment tool whereby gala attendees could indicate interest to participate in an interview. However, the response to the survey was limited, I received four in total, and no one expressed interest in an interview. In hindsight, creating an online survey would have been more beneficial. With so much excitement at the gala and so many people coming and going, few felt compelled to participate. It was difficult for me as a researcher to monitor the survey station, take photographs and conduct participant observation. An online survey, that audience members could fill out on their own time and reflect on their responses, would have been easier for me to manage, may have resulted in more responses and would have, perhaps, compelled a few audience members to participate in an interview.

- Interviews

Roulston identifies six styles of interviews and the theoretical frameworks that underpin them. She argues that understanding the differences in epistemological and theoretical perspectives will better prepare researchers "to use interviews in ways that are consistent with their epistemological and theoretical assumptions about knowledge production" (2010, 51).

Epistemologically, I believe that we come to know the world through subjective experience. If there is an objective world (or historical world as

Nichols (1991, 109) would call it) out there beyond human experience, I do not believe that it is knowable without being, first, mediated through a human being, who is beautifully flawed, terribly inconsistent, and unquestioningly biased. These human characteristics do not contaminate the data, they make the research real, they make it human.

Likewise I believe that knowledge is created collaboratively. Together through discussion interviewee and interviewer co-create knowledge and transform one another's assumptions and views of the world. Therefore, I did not design the interview guides from a neo-positivist perspective, which "assumes the interview subject has an 'inner' or authentic' self... which may be revealed through careful questioning by an attentive and sensitive interviewer" (Roulston 2010, 52).

Instead I borrow from new interpretive and transformative conceptions of interviewing that I feel best match my epistemological stance as a researcher and the moral grounding that researching an emancipatory project with people with developmental disabilities demands. From the interpretive camp, I follow the advise of Norman Denzin who believes that,

> "Doing interviews is a privilege granted us, not a right that we have... Interviews are part of the dialogic conversation that connects all of us to this larger moral community... They transform information into shared experience... They criticize the world the way it is, and offer suggestions about how it could be different" (Denzin 2001, 24).

Similarly, in transformative interviewing together "interviewer and interviewee develop 'transformed' or 'enlightened' understandings as an outcome of dialogical interaction" (Roulston 2010, 66). With these styles of interviewing at hand, I developed my research questions not to merely obtain one-directional information, but to converse and develop our

collective understanding of the stories made for Project Citizenship and how we might perceive and realize a better world inclusive of people with developmental disabilities.

Having previously established a relationship with the leaders at the SKILLS Society who pioneered Project Citizenship, Senior Leader Ben Weinlick and Senior Manager, Community and Leadership Development, Debbie Reid were my first recruits. Ben and Debbie also helped connect me with filmmakers and people with disabilities involved in the project who they felt would be interested in participating in this study. All interview participants were asked if they wanted their real names to appear in this thesis and nearly all agreed. Where participants wished their personal identity to remain confidential, pseudonyms have been used.

From January to March 2013 I held semi-formal interviews with two project leaders at SKILLS, two filmmakers involved in the creation of the stories, and three people with disabilities who have had their stories documented and shared. People with disabilities were given the option of having a family member, ally or SKILLS staff member present to facilitate the interview process. Two brought their support workers with them, who stayed nearby but had little to no contribution to the interview, one of whom left half way through the interview.

I met with interviewees at a place that was most convenient to them. This included going to their office, or home, meeting at a coffee shop or inviting them to my student office on campus. I brought my interview guides and notepad with me, although I tried as much as possible to maintain the flow of conversation and only read from my guides when I felt a natural pause in the discussion and took brief notes when I wanted to keep track of something the participant had said. I also had my laptop, which allowed my participants and I to watch the stories together and comment on them in real time. This was a

particularly beneficial exercise during interviews with people with disabilities (see the Visual Materials – Short Videos section below for further discussion).

For consistency and to facilitate cross participant analysis, all interviewees were given generally the same questions, although there were some differences (see Appendix B). Leaders at SKILLS were asked about the creation and impetus of the project, whereas filmmakers were given specific questions about the editorial choices they made in their stories. Not knowing the level of communication skills participants with disabilities might have, the language of their questions was altered to be more accessible and often reworded in multiple ways, which allowed me to easily approach the topic from multiple angles.

For example, I asked Leaders at SKILLS and creators of the stories the following questions:

1. As a leader at SKILLS, what do the citizenship stories mean to you?
    a. Has your interpretation of the stories changed over time?

2. As a creator or co-creator of citizenship stories, what does the story mean to you?
    a. Has your interpretation of this story changed over time?

However, I adjusted it, as follows, for people with disabilities:

3. Can you tell me a bit more about your story?
    a. What does your story mean to you?
    b. How has telling this story made you feel?

The interviews with people with disabilities were also intentionally shorter, around thirty minutes instead of forty-five minutes to an hour. This was

arranged as not to overly tax individuals with disabilities; however if they expressed interest in continuing the conversation, as was the case with one participant, the interview continued.

All interviews were audio-recorded and I transcribed the interviews myself. I did not mark every breath, pause or inflection in the interviewee's voice, but I did note facial expressions, laughter and physical gestures where I felt they influenced the meaning or tone of the conversation. At times I noticed some participants had trouble answering the question or were confused by my wording. In future interviews I resequenced the questions or changed the language as required.

The interview transcripts were analyzed and coded into themes followed by reflexive note taking. Following Johnny Saldaña's approach to codifying and categorizing, this research went through many cycles of coding whereby breaking the data apart in analytically relevant ways, lead to further questions (2009, 8). The coded interview transcripts were also reviewed in combination with other research data to gain a holistic understanding of the research material and emergent themes.

- Visual Materials - Photographs

With the intent of recording audience reactions and to get a sense of the types of people who attended the exhibit, I took photographs during Project Citizenship's opening night gala. I had hoped to investigate the intertextuality between the stories, examining how different stories/images were arranged in the gallery in relation to one another as well as among people, artwork and physical space. However, the photographs were not as revealing as I had hoped and when researched along with other data, these themes were not as prominent as I anticipated. The SNAP gallery is also a long a narrow space and with over three hundred and fifty attendees the place was packed. Therefore, it was difficult to visually record individual's reactions or gain a

sense of how people might naturally position themselves in relation to the stories.

That said, I was able to take photographs before the gallery got too busy and afterwards when the crowd started to die down. These were particularly useful for recounting how the various video stories were displayed, the quotes presented on the gallery walls and the stories that took on other forms like photographic collections or posters, which are not accessible now that the exhibit has ended. A few of these photographs are included in the subsequent chapters to complement the written analysis and to demonstrate the unique qualities visual materials posses in contrast to written texts.

- Visual Materials – Short Videos

The majority of the stories made for Project Citizenship are short videos and are available online.[3] These materials were analyzed alongside data collected from participant observation, surveys, interviews, and photographs to gain deeper understanding of their significance for various participants and in different contexts. As Sarah Pink professes, "analysis should focus not only on the content of the images, but on the meanings that different individuals give to those images in different contexts" (2007, 123).

As part of this research endeavor I had planned to complete a shot by shot content analysis of the three stories that represent the individuals with disabilities I was fortunate to interview. However, after completing one, it was evident that examining the audio and visual components of each story would be another research project unto itself. Additionally, the findings emerging from surveys and interviews led me to explore a broader range of stories. Investigating a larger number of stories in less detail, allowed me to focus my research on the elements that my informants found most significant.

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[3] Watch citizenship stories online at http://projectcitizenship.com

Moreover, reviewing the story titled "U of A Student Stories – Their Thoughts on Project Citizenship" I gained access to the student experience. Not one of the students I contacted for an interview expressed interest in participating in this study. But, by exploring the general content of this story I was able to ascertain perspectives concerning the project that I was unable to gather through other methods.

As an aside, I would like to reflect on a methodological observation I have made after having viewed stories with informants during interviews. Visual ethnographer Pink cautions,

> Whatever the context, the purpose of this method should not be simply to use video images to elicit responses from informants or to extract information about the images. Rather viewing video with informants should also be seen as 'media ethnography'… This means asking questions such as: How do informant's commentaries on video footage relate to other aspects of their video/media culture? And what discourses to they refer to in their comments and discussion of the footage? (Pink 2007, 112).

While these are valid (and popular) questions in visual anthropology, uncovering the way in which informants situate themselves as viewers in relation to visual material and discourses are not the only topics that can be explored through this method. I agree with Pink insofar as I feel it is important to explore larger societal implications when using film together with interview and that simply seeking responses or reactions to the content of video will not likely evoke anthropologically thick descriptions of culture.

However, in my findings, using film in interview can shed light on the power of stimulated recall to evoke thought (Conners 1980, Tuckwell 1980). Likewise, films can enhance communication and facilitate

participant/researcher rapport, particularly when interviewing people with disabilities who may have problems remembering or difficulties relating to people.

Exploring how people with disabilities make sense of themselves as viewers of their own stories, examining how they relate their experience to other texts, narratives, films and discourses, or locating these stories in film genre contexts of North American society are certainly topics worthy of further study. Within the scope and focus of this research project, I have found using film and interview together to be beneficial, insightful, and anthropologically reveling in areas that do not specifically express results in the from of 'media ethnography'.

In her argument for valid research in the social sciences, Paula Saukko argues for a contextualist validity that refers to "the capability of research to locate the phenomenon it is studying within the wider social, political, and even global, context" (2003, 21). Although this thesis may offer suggestions, it does not spend considerable time or energy making generalizations about the power of story for people with disabilities on a global scale, nor does it explore the meaning of the stories made for project citizenship in a historical or socio-political context. Its not meant to. Rather, as Barone suggests, stories can be evocative in nature, permitting the reader to create meaning of their own (1990).

This study examines multiple voices within a single case study as an exercise in visual anthropology and qualitative research. This project is meant to develop my skills as a researcher: practicing various research methods, performing rigorous data analysis, reporting findings, and uncovering new questions. In other words, focusing on a few individuals in a local

environment has allowed me to fine-tune my instruments for further work in the field.

As Saukko maintains, when approaches to research "argue that they are listening to, perhaps, silenced voices or challenging authoritative discourses… scholars need to resort to some notion of social and historical context and structures of inequality and need some criteria on how to analyze them" (Saukko 2003, 21-22). Through critical reflection, collaboration with interviewees and leaders of Project Citizenship at the SKILLS Society, and comparison of findings against leading scholarship in the fields of narratology, visual anthropology, disability studies and other relevant disciplines, this research situates the social condition of disability and disability discourse within a historical context of discrimination, marginalization and general lack of authority.

However, when it comes to drawing conclusions about the power of story, the potential of audio-visual mediums to further the disability movement or what these stories might mean for others in a larger context, I will leave it up to the reader to draw parallels with the world around them and allow their interpretations of what is presented here to assist them in reaching more general conclusions.

Rationale for Study

Anthropology comes from a long tradition of studying other cultures and writing ethnographies about them; ethnographies that have been highly criticized for their claimed truths, positivistic objectivity, and authoritative slants. The field has certainly come along way since the early days of Boas (1911), Malinowski (1922), and Mead (1928), adopting a self-reflexive approach that attempts to recognize the voice of the author and situate the relationship of informant/researcher within the research activity. Despite

this shift, there remains a lingering ethical unease about speaking for and writing about other people.

The stories and images made for Project Citizenship are inherently tied up with the plight of the disability movement and in my study of these stories I struggle with my role as an able-bodied researcher writing about people with disabilities. In particular this ethical unease exists because there has been direct resistance from people with disabilities who oppose academic study of disability. For example, at the Researching Disability Conference in 1992 in Britain, "disabled people told non-disabled researchers that they had no right to be researching the disability experience" (Shakespeare 1993, 255).

My rationale for pursuing this research begins with a personal introduction. As with Boas, Malanowski, and Mead, my background is in socio-cultural anthropology. As an ambitious (and perhaps a tad naïve) undergraduate student I majored in both Spanish and Anthropology my heart set on traveling through Latin America gleaning as much as possible from new, different, and dare I say *exotic* people living in warmer climates. Since graduation the practicalities of life (finances, career, marriage etc.) have kept me rooted in Edmonton, where my fascination for other ways of living and seeing the world lead me down the less tropical path of grad school. It is here in Edmonton, where my passion for visual arts, storytelling, film, art history, and the lives of others intensified.

Quite rightly, the question could be asked, what does a young women like me, with an interest in art and language possibly have to say about people with disabilities? Put more strongly, what right does an able-bodied, socially privileged, academic female have to write about the lives of people living with developmental disabilities? Does my role as a researcher and my background in anthropology perpetuate a relationship of inequality? Could

this research be seen as exploitation, continuing the tradition of putting words in *other* people's mouths?

To be clear, I am not an authority on the disability experience. My research is an exercise in understanding. I am using the stories made for Project Citizenship as entry points into a deeper discussion *with* people living with disabilities in my community, *with* the people who support them, and *with* the people who document and tell stories about their experiences. Listening to and exploring the perspectives they offer, I hope to expand my understanding of other people's experiences that coexist with my own, perhaps in incommensurable ways.

Instead of strengthening social differences by claiming to be another authority describing, collecting, preserving and documenting what it means to be *other*, I believe my research evokes Homi Bhabha's concept of the Third Space (1994, 55), whereby the disabled storyteller and able-bodied academic blur the limitations of existing boundaries. Working in this third space we negotiate our differences and affinities, explore alternative subject positions and co-create knowledge.

In the case of Project Citizenship, the acts of storytelling and presenting art were public display, and as such they offer an open invitation into the third space as a place for discussion and new understanding. During the first phase of the project, SKILLS publically displayed approximately thirty stories of citizenship at the Society of SNAP gallery in downtown Edmonton. The exhibit opened with a gala event during which the mayor of Edmonton, Stephen Mandel, and the Alberta Government's Associate Minister of Services for Persons with Disabilities, Frank Oberle, spoke about the project. Presented in this setting, the stories invite a conversation with anyone who entered the gallery and paused to observe or listen.

More than casually observing a work of art, the audio/visual realm of short film and digital storytelling further provokes the creation of a third space, inviting viewers into an interactive discussion. By revealing personal experiences, stories create a certain level of intimacy. They draw their listeners in and create a mood of collusion. Personally, I believe in the transformative power of story and academically I am interested in the roles stories play in the shaping of lives and cultures. I am not closely connected with a person with a disability and as an able bodied researcher my position is problematic.

Still, I feel compelled to continue this work as it serves as one exemplar of story as social agent. It is not meant to replace the voices of people with disabilities, but is meant to advance the conversation. SKILLS and the people they support are employing film and art in unique ways and, quite simply, I wanted to be a part of it. What I can add to their cause is academic support, I can ask critical questions and I can disseminate my findings in academic channels. I can contribute within my capacities and to the best of my abilities.

Lastly, I am committed to this work because I am told that it is valued. At the end of our interview Debbie Reid, Senior Manager, Community & Leadership Development at SKILLS Society, made the following remarks:

> Debbie: I think having a formal research arm of the project has really helped us feel credible in our work… I think it's allowed us to be seen as more credible too in the eyes of other people in our world. Whether that's organizations that support people with disabilities, or academic people, you know… in our field and the way we get funding… these days research is… gravy! Maybe twenty years ago… there was a whole arm in our field… that was research, devoted, trained researchers… and that's all eroded over the past while and has resulted in what some of us call the dumbing down of our field… Just as women's studies or feminism

had to fight to be seen as a valid area… that intellectuals should be looking at and developing theory about and so on, that's really eroded I think in many ways, in the way the government funds services in disabilities, yeah so, to have an academic research component to the project I think is really… going to pay off for us. It already has… We we can't pay the kinda wages here to hire people with PhDs, Master's degrees and stuff like that and who've really studied in a really advanced way the kind work we're doing and making links between this kind of work and work of other…community development work… the research component is hugely important to us.

I: Oh, that's great (sigh). Cuz on some levels research can be seen as exploitative, right. Like you're gong in, getting information, taking it back and it only benefits the researcher [or] that type of community, so it's really great to hear that it's valued.

Debbie: Totally valued

In the chapters that follow I will discuss the power of story and what stories and short videos are doing to support the goals and aims of Project Citizenship. Chapter two focuses on stories in a more general sense exploring how they foster the ways in which we perceive, think and learn, how we build communities, strengthen our memories and bring meaning to our worlds. In these respects, stories have tremendous power for supporting the disability movement and improving the lives of people with developmental disabilities

Moving from the general to the particular, the third chapter explores the potential visual stories presented in the form of short video have for challenging social perception of disability, engaging people with disabilities in their communities, and provoking social change. Exploring themes of

expression, accessibility, and literacy this chapter delves into a deeper understanding of what the visual world has to offer people with developmental disabilities.

In an attempt to interpret what the stories made for Project Citizenship have come to mean for audience members, creators and subjects of the stories, the fourth chapter focuses on three major findings: objects, vehicles and inspiration. Examining common critiques of 'inspirational narratives' a large portion of this chapter is dedicated to revealing the complications inspirational stories unearth and recuperating the term so that it may still find a place within Project Citizenship and the disability movement as a whole.

Lastly, the final chapter discusses issues of representation that necessarily come into play when video cameras are set to roll. In a sense this chapter reflects my own journey as I come to an understanding of how my position as an academic (and all my attendant preconceptions) may influence a discussion on representation and ultimately a judgment on the stories made for Project Citizenship and how they were produced.

Throughout this research I have witnessed stories spark human connection and invite intimate interaction. Just as citizenship stories are personal tales, my writing is also a form of story. "Like the artist who uses paint and brushes or the dancer who uses movement, the qualitative researcher uses many techniques as tools to ultimately tell a story" (Janesick 2001, 533). Thus I offer you, my reader, a similar invitation: an invitation to agree, disagree, interpret, contest, react and tell your own stories, as these are essential aspects of discussion. This story is the beginning of an intimate relationship and human connection is a necessary condition for change.

Chapter 2 - Functions of Stories

> If you are a dreamer come in
> If you are a dreamer a wisher a liar
> A hoper a pray-er a magic-bean-buyer
> If you're a pretender, come sit by my fire
> For we have some flax-golden tales to spin.
> Come in!
> Come in!

~ Shel Silverstein 1974

What is the spellbinding power of story? What drives us to tell them? What compels us to listen? As a child I relished in tales of all kinds: poetry, made-up-stories, campfire songs, girly gossip, bedtime books, pop-up books, picture books, movies, cartoons, the list goes on and on. It didn't seem to matter if they were read, sung, told, whispered, or watched stories brought me immense joy and, as an adult, I they continue to tantalize my senses, emotions, and heart's desire.

Such pleasurable entities remain mysterious in their ability to excite, educate and bring people together. Why stories seem such natural methods for communicating human experience has intrigued scholars throughout the ages and continues to perplex experts across disciplines. The research presented here cannot claim resolutions. However, the following chapter attempts to skim the surface of the elusive, cavernous abyss that is story and identify potential insights into what these elusive forms of communication might offer people with developmental disabilities.

According to Barthes (1987), Haven (2007), White (1981) and other experts in the field of narratology, stories are the most basic, universal, and primordial form of communication. They are so essential to human experience, they are thought to precede language and believed to transcend history and culture .

> Story is the root form of all narratives. Story predates logical thinking and argument, writing and exposition, and informative and persuasive structures by tens-of-thousands of years... Every culture, tribe, and nation has developed stories... Not so for writing or logical and expository forms. Story always comes first (Haven, 2007, p. 113).

While the power of narrative and storytelling as been approached from the fields of psychotherapy (Shapiro 1998), education (Connelly 1988, Norris 2000), anthropology (Herzfeld 1986), qualitative inquiry (Reason and Hawkins, 1988), and health professions (Frank, 1996), through my research within the context of Project Citizenship I am particularly interested in the power stories hold for inciting social change and for improving the social condition of people living with disabilities.

Before delving into the details of this research, it is beneficial to first define the terms 'narrative' and 'story'. I will refer to these terms frequently throughout this work and I would like readers to have a clear(er) understanding of my use of the terms, as while they may appear to have similar denotations, their use both within and across academic disciplines is often diverse. In Haven's research on the power of story, he discovered that "authors of fourteen of the eighteen articles... from the field of narratology felt obligated to define what they meant by the word story for the purpose of their study. So did over sixty percent of... sources from narrative therapy... organizational managements, knowledge managements, and cognitive

sciences. Did they all define it the same way? No, not even close" (Haven, 11).

Drawing from the field of narratology, a discipline to which intellectual leaders such as Barthes (1977 and 1981) and White (1981) have made significant contributions, I recognize narrative as both a structural form and a performed experience. As a structural form, narrative is like a scaffold to which characters, settings, events, facts, details, and emotions cling.

Like invisible branches, narratives give support and relative context to these carefully interlaced components, but do so separately from the instrument (words, film, music, performance), which brings such elements to life. As Chatman asserts,

> One of the most important observations to come out of narratology is that narrative itself is a deep structure quite independent of its medium. In other words, narrative is basically a kind of text organization, and that organization, that schema, needs to be actualized: in written words, as in stories and novels; in spoken words combined with the movements of actors imitating characters against sets which imitate places as in plays and films; in drawings; in comic strips; in dance movement, as narrative ballet and in mime; and even in music, at least in a program of the order *of Till Eulenspiegel* and *Peter and the Wolf* (1981, 117-8).

Thus there are many forms of narrative: legal documents, casual conversation, poetry, song, reports, grocery lists, text messages, essays, advertisements, stories etc. These narrative forms differ from each other in the manner in which their components, their textual laundry, (characters, settings, events, facts, details, and emotions) are strung and given prominence within the overarching narrative tree.

25

Extending Chatman's understanding of narrative as structure, especially his examples of plays, films, drawings, dance, and music, narratives can also be understood as performed. That is, narratives do not merely exist on their own as innate structures, they are created for particular purposes and with particular audiences in mind. Thus, a performative approach to narrative also asks, "who an utterance may be directed to, when, and why, that is, for what purposes?" (Riessman 2008, 105).

In relation to research, Richardson believes that all research is a form of narrative stance.

> "Whenever we write science, we are telling some kind of story, or some part of a larger narrative. Some of our stories are more complex, more densely described, and offer greater opportunities as emancipatory documents; others are more abstract, distanced from lived experience, and reinscribe existent hegemonies. Even when we think we are not telling a story, we are, at the very least, embedding our research in a metanarrative, about, for example, how science progresses or how art is accomplished" (1990, 13).

Without relying too heavily on a hierarchical framework, that is without favoring some narrative forms over others, stories can be understood as a specific category of narrative that is both structured in a manner that sets it apart from other narratives, but like other forms, is also intentionally performed. As Dalkir and Wiseman have found, "all stories are narratives. But not all narratives are stories" (2004, 58). How then, would one attempt to define story? Some experts, following the advice of Aristotle, stress the importance of a beginning, middle and end – or at least the sense of an

ending - (Sarbin 1986), while others emphasize a moral imperative (White 1981).

However, the definition I find most robust and useful for this project stems from the definition offered by Kendal Haven.

> "Story: n.: A detailed, character-based narration of a character's struggles to overcome obstacles and reach an important goal" (2007, 79).

I appreciate this definition because it was formulated after extensive research on the subject of story and because it recognizes two fundamental aspects that separate story from other narrative forms. Firstly, Haven's definition recognizes that stories are presented from the point of view of a central character. They are not simply plot-based or event-based narratives, but require a personal point of view, from which they orient the reader. Secondly, more than simply stating that stories have a beginning, a middle, and an end, Haven recognizes that stories conclude or wrap up in a manner that is relevant to the main character. In other words, stories terminate with a resolution that, regardless of realizing a societal moral objective, express a resolution that holds significance from the perspective of the main character.

Where I disagree with Haven's definition is that he requires the central character to struggle and overcome obstacles. Borrowing from Kurt Vonnegut's witty account of story structure, there is little doubt that many story arcs depict the main character suffering some form of misfortune, only to rebound and end up better off than before. These "Man in Hole", "Boy Meets Girl", and "Cinderella" story structures are exceedingly popular and are highly representative of the stories we create, market, proliferate and enjoy around the world (Vonnegut 2006, 25 – 31).

However, there are obvious examples of stories whereby main characters do not 'struggle to overcome obstacles'. Shakespeare's Hamlet and Kafka's Metamorphosis are Vonnegut's chief examples. In these stories, the characters may struggle, but they do not necessarily 'overcome'. On the other side of the coin, stories may simply present events or activities that are meaningful to the main character, but do not always represent a struggle. In Haven's definition the words 'struggles' and 'obstacles' have a negative connotation and not all stories see characters through negative experiences. Some stories are genuinely positive start to finish. What matters in a definition of story is that the events are relevant to both the character and the 'important goal', which is realized through them.

After investigation of the term narrative, and improving upon Haven's and well-researched understanding of story, I present my definition:

> Story: n.: A detailed, character-based narration of a character's activities that realize a significant resolution.

While I have not examined all stories made for Project Citizenship, the three I have closely interrogated (along with others more loosely), certainly fit this definition of story. They are character-based, they show these characters performing activities that are both important to the main character: cleaning out stables and helping children ride horses, teaching children basketball, socializing animals etc.; and the activities are relevant to the resolution offered by the tale: people with disabilities are engaged citizens.

Certainly some citizenship stories do show an individual with disabilities struggling and overcoming obstacles, a contentious issue I examine in further detail in chapter four. However, as Vonnegut recognizes, it is important to break away from story structures that oscillate along the good fortune/bad fortune gradient. Using the example of Hamlet, Vonnegut writes,

"Shakespeare told us the truth, and people so rarely tell us the truth in this rise and fall here [indicates blackboard]. The truth is we know very little about life, we don't really know what the good news is and what the bad news is" (2006, 37). Therefore taking 'struggles' and 'overcoming obstacles' out of the definition of story, allows us to include a larger range of narratives under its umbrella and enables us to freely part with predicable storylines that necessitate a moral judgment on events which could be read as either good or bad news.

With this understanding of narrative and story in mind, I move toward an analysis of the stories made for project citizenship and how this narrative structure is well suited to the goals of this project.

The Power of Story

In *Story Proof: The Science Behind the Startling Power of Story*, Haven (2007) synthesizes the findings of over eight hundred studies researching the power of story. He concludes by summarizing eight prominent themes, four of which I feel are of particular relevance to Project Citizenship. Using Haven's results as a guide, I will discuss how using the narrative structure of story has particular benefits for a project aimed at facilitating community outreach for people with developmental disabilities and for inciting social change.

- Stories are How Humans Perceive, Think and Learn

Sitting around the breakfast table with a few girlfriends and their children, one close friend asked me how my research was going. As I was describing what I was learning about the power of story, she turned to the kids and asked, "Why do you think stories are so important?" I was intrigued (and delighted) by her decision to include the children in the discussion. After all, they are notable experts on the subject (myself having the enjoyable

experience of reading bedtime stories to them on more than one occasion). My dear friend's six-year-old son was the first to respond. Eagerly looking up from his bowl of yoghurt, granola and summer berries he said, matter-of-factly, "Because you learn something!"

Quite an astute response from a kindergartener! And his conclusions are not unfounded. As research suggests, stories have considerable potential to educate. "More than just being a uniquely effective learning, teaching, and communications tool, a number of studies have extended their research to show that the reason behind this unique effectiveness is that stories match how humans naturally perceive, process, think and learn" (Haven 2007, 103). Simply put, "we humans live, think and learn through stories" (Haven 2007, 104).

If researchers (of all ages) can easily identify the importance of stories, it's no wonder Project Citizenship was drawn to this medium. One of the major goals of this project is that audience members can take away valuable lessons: a deeper understanding of the meaningful contributions and personhood of people with developmental disabilities. What better way to inform and educate than through the narrative form that most accurately resembles how humans think and learn!

As "human beings think, perceive, imagine, interact and make moral choices according to narrative story structures", the stories made for Project Citizenship, thus, have the potential to teach audience members about and influence their behaviours towards people with disabilities (Sarbin 1986, 8). Having a tool that can effectively influence social perception of disability is invaluable to this project.

- Stories Create Involvement and a Sense of Community

To draw the conclusion that stories create involvement and a sense of community, Haven synthesizes data from a number of studies, which examine the use of storytelling to facilitate organizational change within corporate institutions.

> The common thread in each of these case studies is that an organization found that stories were more effective than what they had been using to accomplish essential internal community building, to create a sense of involvement, and to instill organizational attitudes, beliefs, and perspectives in organizational members (Haven 20017, 111).

Creating involvement and a sense of community is important for both the SKILLS Society as an organization and for Project Citizenship as an action research project seeking social change. In order for Project Citizenship to be successful, SKILLS needed understanding and support from staff working at all levels within the organization: front-line care givers, team leaders, and management. In bi-weekly meetings called Think Tanks, staff members frequently met to discuss the project's goals, better define citizenship, discover new ways to engage the people they support in community life, and yes, share stories!

As the first citizenship stories were made, they were shown to other staff members to help get them excited about the project and inspire them to think about the kinds of stories they could help create for the individuals they support. Research shows that using stories in this context is one of, if not the best, method for obtaining group cohesion. For example, "Motorola's vice president for human resources and organizational development trains managers in storytelling because they have found that storytelling is "fun and more effective at establishing corporate direction and identity"" (Haven

2007, 111). This is great news for SKILLS as an organization, using story they can best achieve institutional cohesion and orient organizational activities in a common direction.

However, the comradery associated with sharing stories is by no means limited to the corporate realm. While Haven's research focuses on studies that examine the potential for stories to strengthen community within organizations, it is not difficult to extend the organizational group presented in these findings to include a larger public body. He claims, "stories connect each receiver to others, form bonds, create common identity and purpose, and encourage people to adopt the values, ideas, perspectives and attitudes of story characters. These elements, in turn, build a feeling of involvement and a sense of community" (Haven 2007, 113).

While Haven argues that stories have the potential to create a sense of involvement, a senior filmmaker I interviewed, Lorraine, shed light on *how* stories can foster community building.

> Lorraine: You know what I think it does, its not just the end result, the actual making of this, it's hugely community building (laughs). Like the involvement between SKILLS and the students, the process of just dialoguing, talking and whatever and then taking the reins and making something. It's huge... its not just sort of having a story finished. The process of getting the story is as valuable that's almost more valuable to the people who were involved and potentially [has] the longest lasting affect.

For Lorraine, its not necessarily the finished product that has the greatest impact, but the collaborative act of story making that brings people together in meaningful ways. Having students, people with disabilities and staff at the SKILLS society working together to tell stories, builds a sense of involvement

and community connection. The activities of creating and sharing stories have a larger capacity to bring people together than the product alone.

By viewing citizenship stories, members of the general public are engaging in a similar dialogic activity with the storyteller and, thus, are able to make connections and relate to the experiences of people with disabilities. Ultimately, citizenship stories have the power to re-align participant's attitudes and beliefs with the messages they present. As Haven reveals, studies have "confirmed the power of story to motivate readers and listeners to pay attention and to internalize and adopt the content being communicated." (2007, 112). Beyond the SKILLS Society as an organization, citizenship stories are capable of creating a common perspective between the general public and people with disabilities surrounding their belonging and worth in society and enhancing people's ability to empathize with another's social, physical, and cognitive condition.

With a major aim of project citizenship being to challenge social perception of disability, choosing 'story' as their primary method of communication could not have been more apt. Creating involvement and a sense of community is critical for social change and there is no better narrative form to achieve these goals than through story.

- Story Structure Enhances Memory

Another valuable result Haven posits in his analysis of story and story research is that using story structure enhances memory. Improving memory is of particular importance for people with developmental disabilities because most, at the very least have trouble remembering and many suffer significant reduction in the cognitive functioning of their short-term and/or long-term memories.

In Haven's report, "all studies agree that stories provide a structure that facilitates (improves) memory and long-term recall of key content" (Haven 2007, 119). It is unknown if any of the studies Haven reviewed studied memory enhancement for people with developmental disabilities. But theoretically, if stories are proven to improve memory for people who do not struggle with memory, it seems likely that the benefits for people who do present cognitive impairments would be similar if not more pronounced.

Discussing the connection between memory and citizenship stories with Debbie, she offered the following insights. I have italicized few words in this passage to emphasize her thoughts on memory. This segment is reintroduced later in the chapter and interrogated from another, albeit related, perspective.

> I: Really cool. And it makes me think of um like *memory making*
>
> Debbie: Yeah. Exactly. *Memory making*, yeah. Because people's I mean, the definition of, many people with cognitive disabilities have poor *memories*… and *memory* problems so they need more help with *memory keeping* and *making*. And they *get less* you know, cuz we write notes about them and how does that help them *remember* stuff? And they can't, lots of people can't even talk. They cant even say, you know "this is what we did this week" or "this is where I went" you know. They need a tool like a photo album or a little video or whatever to be able to engage and say "Hey this is what I did, this is who I am."

According to Debbie, stories are an exceptionally potent tool to give to people with disabilities who, almost by definition, struggle with memory! Within this relatively short statement Debbie recognizes that stories target an area where people with disabilities typically "get less." With proven ability to

enhance memory, stories have the power to significantly improve the lives of people with disabilities because they stimulate and strengthen a primary deficiency experienced by many people with developmental disabilities: memory. If such simple and potent prosthetics exist, its surprising that stories are not created and shared all the more frequently and abundantly.

Beyond the support of relevant literature, and more than taking Debbie's word for it, there is evidence (although arguably anecdotal) in my research that supports the notion that stories can improve the memory for people with developmental disabilities. The people I interviewed for this study were exceptionally high functioning. All had strong communication skills and I was surprised by both the ease and flow of our conversations and their ability to articulate fairly complex ideas. However, each individual I spoke with had trouble with memory. At one point or another during the interview, there came a moment when an individual came right out a said "I forget" or "Oh I [can't] remember, I'm not so good."

During my interviews with people with disabilities, I would offer to watch their story with them. Most were eager and excited to do so and I found this practice extremely insightful. Observing, listing to or discussing moments in the story, it was clear how much stories aid memory. It was almost magical, to see memories coming back to them and like a trigger the story would spark other memories and the participants would introduce new stories to our conversation.

Take my conversation with Wes for example. Wes volunteers at Lit Bits Therapeutic Riding Society where he leads horses for children riders with disabilities. While watching his story about his work there, the following interaction transpired between us:

Wes: That's ah that's one of the one of the volunteers, talking there. You see the guy on the horse?

I: Um hm

Wes: His name's Teddy. He um I usually lead him all the time, but he doesn't ride anymore, he's too ill right now

I: Oh that's too bad

Wes: So he doesn't come anymore (sounds sad)

Video: When I first met Teddy a year and a half ago, we could barely keep him on the horse

Wes: Oh yeah that's true (laughing) we couldn't keep him on!

I: (Laughs)

Wes: That's true

Video: We had to bring in a new horse for Teddy

I: Do you remember that?

Wes: Oh yeah

I: How was that?

Wes: It was ok

I: It was ok?

Wes: I still lead it

I: You still [lead it], wow

Video: We asked Wes to step aside and let someone else lead

Wes: Oh yeah, I remember that

… (later in the interview)…

Wes: I got, now I got one little, one little favorite rider now in place of Teddy

I: Um hm

Wes: Ah is name's, what's his name, um Arthur. He's just a little, he stands oh he's about this big (holds his hand just below table height)

I: Oh wow

Wes: Oh, every time I come near him (smiling), one time he said "Where's my favorite leader?" (laughs) "Oh he's coming he's coming, don't worry," I show up, come around running toward me, give me a big hug and said "You going to lead me today," I said "Yeah I'll lead you today."

During this exercise of watching the story with Wes, a few important points come to light. Firstly, it is clear that stories enhance memory. When the video states, "when I first met Teddy a year and a half ago, we could barely keep

him on the horse" and Wes responds in laughter "Oh yeah that's true, we couldn't keep him on!", it is obvious that story is helping Wes recall a special moment in his life. The joy in the room is almost palpable. The short video also helps Wes recount an event he didn't recall correctly. While he remembers having to bring another horse for Teddy, he remembered leading him that day. But when the video indicates that Wes was asked to step aside, he changes his version of the story and says "Oh I remember that." This may be a small example but it illustrates that stories have the power, or at least the potential, to enhance memory for people with developmental disabilities.

Another significant insight from this encounter is that the story sparked other memories that were not present in the video. After Wes was triggered by the story to think about Teddy, he volunteers another story about his new rider Arthur. It is possible that stories not only enhance memory of the particular events and people in the stories, but enhance memory recall of other related events as well. If this is true, (undoubtedly more research with people with developmental disabilities would be required), stories could be profoundly advantageous for assisting people who struggle with memory.

As well as improving the lives of people with disabilities, enhancing memory is also important for audience members who view the stories. As Haven posits, "certainly a major goal of all communication is to place information into the memory of receivers so that they can recall and act on that information"… "More importantly, since meaning is the process of creation within the mind of the receiver, your use of story structure better insures that meaning created by the receiver will more closely match the meaning you intended to create" (Haven 2007, 118 and 108).

Accordingly, a major goal of Project Citizenship is social change and the creation of citizenship stories was partly aimed at transforming the perception of people with disabilities in the public eye and altering the way

many people act (discriminatorily) toward them. Appropriately, there is further research to suggest that stories can be powerful change agents.

> Braun-LaTour and Zaltman (2006) report on an experiment they conducted. Moviegoers recorded their initial impressions of a movie immediately after viewing it. Some of those expressing a negative opinion were, later, shown a positive review of the movie and then asked to recall and describe their initial opinion. Virtually all recalled their initial opinion as being more positive than it had been- though none thought they were changing their initial opinion in any way and all believed that they were accurately recalling their initial statements. Others who were not shown the positive review accurately recalled their initial negative opinions. Merely reading a positive review affected how people recalled their own memories (Haven 2007, 70).

While Haven presents this study as an example of how audience members incorporate new information into their memories, in my reading, this study is an example of how the introduction of positive stories can change people's minds. If such research is true, audience members who view the stories made for Project Citizenship are likely to incorporate an understanding of people with disabilities as engaged citizens into their memories. This means citizenship stories have the potential to adjust viewers' preconceptions of people with disabilities, rewire their negative past encounters, and alter how they remember other narratives and discourses concerning disability in society. As Swatton and O'Callaghan assert in their grounded theory study on the healing power of stories, "we cannot change ourselves until we change our stories" (1999, 413).

It is interesting, however, that in Braun-LaTour and Zaltman's study, the participants were asked to 'read' the positive review. In his own study, Haven

carefully considers a story's method of delivery (told vs. read) and its effect on memory recall. He concludes that, "storytelling (orally telling the story) is the most effective means of placing story information into student memory… When program plans permit, story*telling* maximizes the positive effects of story structure" (Haven 2007, 120).

This is similar to what I have found with audience responses to Project Citizenship's gala event. Although my survey did not directly ask a question on the matter, nearly all respondents indicated how much they enjoyed meeting and speaking with people with disabilities about their story. Most frequently, this response surfaced to the question:

Are there any stories in particular that stand out for you? If so, how come?

A2: Eric's story stands out, mostly because he explained [to me] how he found his job on his own. A tremendous feeling of confidence.

A4: The 'Model Employee'. This story was really inspiring. We also were able to meet the person who the video was about.

It is not that having the story told orally was important to viewers at the gala, but having the human interaction and discussion with people with disabilities that makes the story stand out. While audience members find meaning in the videos themselves, the personal interaction with people with disabilities at the gala, was value added. Although more research is required, I would be curious to explore what makes story*telling* "the most effective means of placing story information into… memory"? How much weight is put on the method of delivery vs. having face-to-face interaction with the storyteller independent of the medium? Given the information audience members have revealed, I imagine that human connection weighs as heavily,

if not more so, on the receiver's ability to recall a story (not to mention the gravity and personal import he/she places on it) as does the manner in which it was delivered.

In this example, the importance of a performative approach to all forms of narrative is revealed. As Richard Bauman states, "not an insignificant part of the capacity of performance to transform social structure… resides in the power that the performer derives from the control over his audience afforded him by the formal appeal of his performance" (1977, 16). Using the narrative form of story, then, affords the storyteller significant control over his/her audience and has the capacity to transform social perceptions. More than a structure, narrative as performed, especially within a personal encounter, holds considerable power to persuade and influence audience members.

- Using Story and Story Structure Enhances Meaning

Returning to Debbie's quote above, she brings to light that having the ability to replay and revisit past experiences and human interactions, citizenship stories allow people with disabilities to build a stronger sense of continuity with people in their lives and facilitate the development of their individual identity.

> Debbie: … they need a tool like a photo album or a little video or whatever *to be able to engage* and say "Hey *this is what I did, this is who I am*".

In this sentence, Debbie is alluding to the conclusion that memory and self-representation are critical for constructing human identity. She is not alone in this assumption. As Neuropsychologist Hans Lou maintains, "for a

coherent and meaningful life, conscious self-representation is mandatory. Such explicit "autonoetic consciousness" is thought to emerge by retrieval of memory of personally experienced events ("episodic memory")" (2004, 6827). Thus story making and storytelling, beyond enhancing memory, can help people with developmental disabilities to make sense of who they are, construct and assert their individuality and develop a more coherent and meaningful life.

Physician Lewis Mehl-Madrona agrees that stories enable human beings to find meaning in their experiences.

> "Narrative psychotherapy says that stories contain our experience and the meaning we make of that experience. We communicate about our world by telling stories. Stories hold the richness and the complexity that simple declarative facts can never grasp"... [story] provides the dominant frame for organizing experience and for creating meaning out of that experience" (2005, 152).

Other scholars present similar perspectives. Heidegger has proposed that human experience in its original form is hermeneutically meaningful and narrative is a primary scheme by means of which hermeneutical (interpretive) meaningfulness is manifested (Haven 2007, Polkinghorne 1988). Daniel Taylor claims, "you *are* your stories. You are the product of all the stories you have heard and lived... They have shaped how you see yourself, the world, and your place in it" (1996, 1).

Therefore, citizenship stories have the potential to help with people with disabilities find meaning in their lives. Having a story about her job at the movie theatre, his t-shirt business, his neighborhood vigilantism, these activities are imbued with deeper significance. In this sense the stories made for Project Citizenship are transformative, they become a vital element in

shaping how people with disabilities imagine themselves and see themselves as active participants in society.

A major goal of Project Citizenship is to improve the lives of people with disabilities by engaging them in community. These stories help to solidify community engagement as a significant activity in the lives of people with disabilities. Stories help them imagine better lives for themselves and help elevate people with disabilities to a position where they can be understood and respected as equal citizens. "Philosopher Isak Dinesen said, "To be a person is to have a story to tell"" (Haven 2007, 10).

In his analysis not of what stories are, but what they can do, Haven recognizes that stories have unique qualities for (among other things) matching how humans think and learn, creating a sense of community, enhancing memory and creating meaning. When well constructed, stories ensnare their readers, listeners and viewers, in a web of concentration and awe unparalleled by other narrative forms.

Examining the conclusions Haven draws, there are obvious connections between the power of story as analyzed in his research and the potential for the stories made for Project Citizenship to support its social justice cause. Stories have the ability to teach, instruct and help us learn. Enabling involvement and a sense of community, stories are important for the SKILLS society as an organization, for people with disabilities looking for inclusion in community groups, and audience members who can expand their concept of society (and consideration of citizenship) to include people with disabilities.

By enhancing memory, stories are powerful prosthetics for people with disabilities who often suffer deficiencies in memory retention (Mitchel and Snyder 2003). Audience members also benefit from viewing citizenship stories as they influence receivers' memories and thus their opinions

concerning and behaviors towards people with disabilities and their place as equals in our communities. Stories also aid 'hermeneutical meaningfulness', which allows people with disabilities find significance in their lives and establish their place in the world.

Figure 1

To be frank, I had some difficulty writing the introduction to this chapter. It felt harsh, awkward, and almost confrontational to begin an investigation into the importance of images and the visual nature of the stories made for Project Citizenship by first presenting my audience with seemingly staunch, rigid, and unyielding printed text. In a search for alternatives, I went looking for images 'Googling' phrases like 'why art? or 'why images?' to see if I could find a gentler, more inviting presentation that might better set the tone for this discussion.

Within the top thirty or so hits, I came across the photograph above. I immediately recognized it as an image I 'liked' or 'shared' on Facebook in the past few months and I was drawn to it as much then as I am now. Admittedly,

it does not completely match the arguments and findings that follow, but I feel it captures a remarkably similar sentiment. At a glance I see joy, innocence, learning, mimicry, and freedom. Aware of myself as a watcher watching the watcher, a meta-viewer, I see invitation and participation: call and response. Highly accessible, I see the painting's message strike a young child with the accuracy and precision of a dart. It is as if I am witnessing Barthes' concept of punctum in action, this intangible, yet poignant "element which rises from the scene, shoots out of it like an arrow, and pierces" (1981, 26).

While the written word is undoubtedly valued and valuable, it has its limits. There are messages and knowledge that visual materials: images, paintings, videos, photographs etc. can communicate in such exact and non-articulate (embodied) ways, that it would seem absurd to attempt communication by any other means. Sawyer and Norris claim that artifacts add "'contexture', or texture of the context that enhances the effectiveness of the text. In addition, through juxtaposition with the printed text, the pictures create an intertextual subtext as the artifacts generate new, nonverbal meanings for the readers" (2013, 86).

Using the above image (and a plethora of others) as tools to think with, I am compelled to question the importance of the medium for delivering particular content. Are some methods of delivery better than others?

> As a small section of his unpublished doctoral work, Janner (1994) conducted an interesting study with four fourth-grade classrooms. He delivered the same story to each class. To one he read the story; to the second he gave copies of the story and had students read it; to the third he showed a video of the story; and to the fourth, he told the story. One month later he interviewed selected

students from each class to see how the medium of delivery affected their long-term memory of the story.

The students who most accurately recalled the story and its images came from the class that had seen the video. However, they typically required extensive prompting to activate those remembered images. The students who where most enthusiastic and excited about their recollection of the story, who most readily recalled the story without prompting, who held the most vivid and expansive images of the story and who were best able to verbalize their memory (and version) of the story were those from the class to whom he *told* the story (Haven 2007, 121).

While telling stories may facilitate long-term for memory recall in fourth graders, as a novice visual anthropologist, I am curious to investigate how visual materials can support a project aimed at engaging people with disabilities in their communities and challenging social perception of disability on a larger scale. Why did Project Citizenship choose video as its primary medium? What can short videos do that other forms cannot? Having explored the unique attributes of story and the appropriateness of this narrative form for Project Citizenship in the previous chapter, this chapter discusses the visual quality of citizenship stories and the potential visual mediums hold for facilitating an emancipatory project with people with developmental disabilities.

When I asked Lorraine if she thought there was anything that film, as an audio-visual medium, might lend citizenship stories that another medium might not, she chuckled as she emphatically said,

Lorraine: Yeah. You get to see it! (laughs) You totally get to see it. I mean film brings things to life. Yes you can interpret it… you could

make an experimental film... but you really can get a good picture of somebody and their life through film. You can step into their world for a minute and see them looking pretty real (laughs).

In the short videos made for Project Citizenship audience members are not merely *told* the stories of people with disabilities acting as engaged citizens, they are *shown*. We see the movement of bodies in motion, we witness interactions between people and come to know these individuals through observing their activities. Through sight and sound we are granted access into people's otherwise private worlds.

More than showing, videos and films are also expressive media. In *Storytelling as Inquiry*, Reason and Hawkins present the distinction between explanation and expression "as two basic modes of reflecting on and processing experience... Explanation is the mode of classifying, conceptualizing, and building theories from experience" whereas "expression is the mode of allowing the meaning of experience to become manifest" (1988, 79-80). While these two modes are not mutually exclusive, videos can certainly explain as much as they express, Reason and Hawkins "see explanation and expression not as competing modes but as poles of a dialectic" (1988, 83). The amount of one or another, or both are present in a story is dynamic and in constant flux.

However, I would argue the audio-visual medium of video allows citizenship stories more opportunity to express their meaning. For example NAIT student and up-and-coming filmmaker Steven Cresswell offers the following discussion on Daniel's Story, Drumming to His Own Beat,[4]

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[4] Watch Daniel's story online http://projectcitizenship.com/daniels-story-drumming-to-his-own-beat

Steven: For an example… Daniel the drummer, we were interviewing his friends at the drum circle, we had Daniel sit by the people as we were interviewing them and so for Daniel you know when he's hearing these people saying great things about him… it means a lot to him just sitting there and so he was pretty happy by the end of the day and you could see on his face what his friends were saying about him meant a lot to him… One friend who was saying how he was very expressive with his face, cuz he is very expressive, and as she was describing his expressions and what he does with his expressions, he started to do them as she was describing them…and like they're both laughing about it. So that was an example of showing you know they're friendship, showing that's the side to him you wouldn't know unless you know him.

In this example the story's meaning: Daniel's friendship with his peers, is expressed through eye contact, smiles, conversation and laughter. The human connection we perceive is not explained, but expressed through a combination of audio and visual cues. In essence we are witnesses, or accomplices to Daniel's experience and come to know the affinity he shares with others by what is expressed on screen rather than explained.

It is this expressive quality of video that makes them particularly potent for inciting social change. According to Debbie's observations, people respond better to examples and expressions than they do to mere explanations, particularly when it comes to training SKILLS staff.

Debbie: The films and stories have really been helpful to people to, you know, wake people up out of the snoozing that sometimes can be (laughing) from training… so they're really potent tools… People find them immensely helpful. We get a lot of feedback… and you can just feel you see people smiling and eyes twinkling or crying you know, people are inspired, people are moved by them in a way that um I suppose if

you're a really really good storyteller without visual images, you know
some people are gifted that way (laughing), lots of us aren't and so
these stories... are just very helpful in that regard.

While Debbie recognizes that non-visual mediums can be impactful, she
attributes the powerful, expressive qualities of the videos to their visual
elements.

Their life-like appearance, the invitation into another's private world, and the
ability for audiences to witness the experiences of others, give films and
videos tremendous capacity for expression. Instead of theorizing and
classifying, expression allows the meaning to become manifest.

Accessibility

Beyond their expressive capacity, another major benefit of presenting
citizenship stories as short videos is accessibility, a long-standing hot topic in
disability studies. From the nineteen sixties to the nineteen eighties, in what
could be considered the first wave of the disability movement, activists in
Canada, the United Kingdom, and the United States (and the world over)
followed the direct action model exhibited by the women's and the African-
American civil rights movements. Using highly visible demonstrations and at
times controversial actions, protesters targeted institutions responsible for
creating and maintaining disability as an oppressive social construct
(Shakespeare 1993, 251). The public sectors of transportation, education and
employment were (and still are) popular targets.[5]

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[5] In the summer of 2010 the Canadian Disability Policy Alliance Secretariat
published a report titled "A Canadians with Disabilities Act?" which explores
the need for a federal disability policy in Canada. (Incidentally, such an act
was promised in 2004 as part of the Harper government's election platform).
Data in this report "reveals that legislative and bureaucratic attention has
been concentrated in several priority areas; namely employment,

"There is an unsubstantiated story that New York wheelchair users enlisted the support of the Weather Underground to dynamite undropped kerbs" (Shakespeare 1993, 250). Similarly, the Campaign for Accessible Transport (CAT) in Britain, lead a protest in London during which wheelchair users chained themselves to buses. Ironically, "proceedings against arrested protesters at Horseferry Road Magistrates Court had to be terminated, as the building was inaccessible to disabled people" (Shakespeare 1993, 250-252).

More than relying on direct action demonstrations, activists and scholars furthering the disability movement today recognize the potential for new technologies (internet, mobile phones, virtual reality etc.) to both assist people with disabilities in their day-to-day lives and further their cause from innovative, effective and influential new platforms (Ginsberg, 2013, Manning 2010, Rose 1996, Wade 2001).

Speaking at the Richard Frucht Memorial Lecture and Student Conference at the University of Alberta on February 27, 2013, Faye Ginsburg (David B. Kriser Professor of Anthropology at New York University) gave a public lecture titled, "Disabilities in a Digital Age: Rethinking the Human Imaginary on and off Screen." Her lecture discussed "how, in the 21st century, people with disabilities are developing emergent forms of digital media practices that enable their own self-representation in ways that slowly but surely are expanding our collective sense of personhood and publics" (Ginsburg 2013). The cases she explored "are exemplary of the enhanced capacity of digital media to provide counter-discursive sites of representation for cultural actors who rarely have had opportunities to enter the public (or counter-public) sphere" (Ginsburg 2013).

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transportation and income assistance" (2010, 10). Accessibility to transportation, jobs, and a minimal standard of living are key topics for people with disabilities in living Canada today.

With the abundance of new technologies such as YouTube, Netflix, smart TVs, smart phones, Wi-Fi, 3G, social media sites etc. it is becoming increasingly easier to access visual media. YouTube alone demonstrates the popularity and pervasiveness of short films and video clips. (I've lost count of how many social gatherings with friends and family have turned into YouTube parties). With Internet connections spanning the globe there is unprecedented potential for one's home movies to 'go viral' reaching millions of viewers plugged-in around the world.

This technology presents potential proliferation of material that was unthinkable in previous generations and this platform offers people with disabilities (and the people who support them) a new and powerful avenue for disseminating their stories. The people I spoke with for this study were keenly aware of the far-reaching potential of video storytelling. Senior Leader at the SKILLS Society Ben Weinlick commented:

> Ben: That's one of the hopes that people take away… That they become shared, the stories, it would be great if the stories become viral, become shared and go around and people go "Oh, did you see this?"

Similarly, Steven remarked:

> Steven: "I love how easy it is to share visuals online".

However, despite the excess of digital media technology, accessibility is still an issue for people with disabilities.

As Steven later stated,

Steven: I think the video stories are perfect for sharing online, you know its easy, anybody can pop up and *watch them for free* so these are something that could continue to be watched for who knows how many years, so absolutely I think that they will make an impact.

However, the Internet is not free. When speaking with Wes about his story, he mentioned that he did not watch his story online because he does not have access to the Internet. A senior living in a care facility, Wes found that having to personally pay for the Internet was prohibitively expensive. The vast majority of people with disabilities, "share a condition of poverty" and many still live in group homes or public institutions where having luxuries such as the Internet are easily deemed a superfluous and unnecessary expense (Shakespeare 1993, 255).

While access to technology is getting better, it is important to recognize that for many people there are still very real limitations: institutionalization and poverty being obvious inhibitors. Until these social constraints are sufficiently addressed, people with disabilities will continue to be disproportionately deprived of the tools, services and technologies that able-bodied citizens enjoy and often take for granted.

That said, creating citizenship stories in the format of short videos, Project Citizenship can take advantage of the benefits offered by the Internet by easily sharing stories of engaged citizenship with new and diverse audiences around the world. Uploading videos to the internet taps into a growing trend in our society whereby people of all ages and abilities are becoming exceptionally proficient with watching and sharing videos both in person and online via social media. There is room for improvement, but the format of many of these stories offers a significant opportunity for people with disabilities to interact and engage with others like never before.

<u>Literacy</u>

Another remarkable benefit of creating citizenship stories in short video form, stems from their visual nature. Many scholars have observed that beginning with the modern era, people (particularly in the West) have expressed an overwhelming preoccupation with the perception of sight and all things visual (Berger 1972, Classen 1993, Jay 1998, Jenks 1995, Mitchell 1994, Ong 1988, Pinney 1992, Rose 2007). Above all other senses: touch, taste, smell and sound, sight has become the "master sense" (Jay 1998, 66). Perspectival painting introduced during the renaissance together with technologies such as the printing press, telescope and microscope claim responsibility for ushering in an era "considered resolutely ocularcentric" (Jay 1998, 66).

Moreover, such empirical, scientific and quantifying technologies have secured the throne for sight as the ruling sense by inextricably linking it with knowledge. "It is suggested that modern forms of understanding the world depended on a scopic regime that equates seeing with knowledge" (Rose 2007, 3).

> 'Idea' derives from the Greek verb meaning 'to see'. This lexical etymology reminds us that the way that we think about the way that we think in Western culture is guided by a visual paradigm. Looking, seeing and knowing have become perilously intertwined. Thus the manner in which we have come to understand the concept of an 'idea' is deeply bound up with the issues of 'appearance', of picture, and of image (Jenks 1995, 1).

> As a concept and term, 'world-view'... reflects the marked tendency of technologized man to think of actuality as something essentially picturable and to think of knowledge itself by analogy

with visual activity to the exclusion, more or less, of the other
senses (Ong cited in Classen 121).

Relying on primarily visual stories to communicate its message, Project Citizenship is capitalizing on our societal predominance of vision. However, not all images, nor visual activities, are created equal. Without carefully considering the hierarchical power structures at play, we loose *sight* of the most powerful and influential technology implicated in the concept of 'seeing is believing': the written word. The activities of reading and writing are irrefutably visual and while common phrases such as 'a picture is worth a thousand words' permeate our culture, the written word tends to trump all other forms of knowledge (visual or not).

In his discussion on *Writing as the Measure of Civilization* William A. Graham posits,

> It is hard to overestimate the perceived significance of writing to a
> literate culture. Virtually every culture that has mastered the art
> of writing… has assigned immense importance and prestige to the
> written word… where writing has been more widely
> disseminated, its prestige has been tied up with the economic or
> social advantage that it confers in those who can master it; and
> where moveable-type printing has joined with other forces to help
> expand the literate population, writing and reading have become
> necessities for full participation in the larger society (1986, 12).

On overarching meta-narrative in early anthropological inquiry believed that people naturally progressed from primitive to civilized. Encountering people living in other parts of the world, in cultures distinct from their own, ethnographers believed these 'Others' to be a missing link to the past,

prehuman relatives who, despite living in the modern era, had not quite evolved to a Western state of advancement.

A distinctive marker along this evolutionary cycle was literacy. Those who had developed a written language were, naturally, more advanced intellectually and thus culturally superior human beings. "The Egyptologist Alan Gardiner has remarked that "man's successive discoveries, at very great intervals, of the respective techniques of Speech and Writing, have been the two main stages passed by him on his long road to civilization"" (cited in Graham 1987, 12).

This evolutionary understanding of human civilization is ostensibly discriminatory, yet it retains a tight grip on Western ideology today. This day and age the literacy is still used as pejorative sign to disassociate (and dehumanize) others who cannot read or write. For example, in his study of post Apartheid South Africa, Adrian Blackledge claims, "for many groups, their literacies are marginalized and undervalued by those who have the power to decide which literacies have status in society" (2000, 21).

Blackledge's use of multiple literacies is compelling because it shifts the metaphorical supremacy of written literacy and brings it in parallel with other ways of knowing. One can be literate in the written realm or literate in film, in art or demonstrate competency through embodied knowledge. Labeling all epistemologies as 'literacy' works to deconstruct the hierarchical power structure that favors written forms of knowing over other forms.

In her 2007 YouTube video titled, *In My Language*[6] Amanda Baggs presents a similar argument. Instead of critiquing the authority of the written word, she voices her frustration with the superiority all linguistic forms of

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[6] Watch on YouTube: http://www.youtube.com/watch?v=JnylM1hI2jc

communication. In this eight-minute clip, she depicts her world as a non-verbal autistic woman. Highly tuned into her surroundings, we see Amanda experiencing her environment through repetitive movements, excessive touching and monotonous resonating sounds.

About half way through the video Amanda's voice comes in. To be more accurate, it is a computer-generated voice that speaks the message Amanda has typed out. In this section of the video viewers learn how Amanda feels about discrimination towards people with disabilities. In a well-articulated and hard-hitting monologue she expresses her concern for how people who cannot communicate through conventional (linguistic) channels are treated as sub-human, incapable citizens with nothing to say.

On Anderson Cooper's blog, February 21, 2007 Amanda writes:

> My viewpoint in the video is that of an autistic person. But the message is far broader than autistic people. It is about what kinds of communication and language and people we consider real and which ones we do not. It applies to people with severe cognitive or physical disabilities, autistic people, signing deaf people, the kid in school who finds she is not taken seriously as a student because she does not know a lot of English, and even the cat who gets treated like a living stuffed animal and not a creature with her own thoughts to communicate. It applies to anybody who gets written off because their communication is too unusual.

Amanda's literacies are not achieved through the verbal communication, much less the written word and her embodied knowledge realized through taste, smell, touch and sound are easily discounted. It is not until she communicates in a linguistic form (through sub-titles and a computer

generated voice) that we recognize her behaviours as intelligent and meaningful.

This video is a potent example, imploring viewers to question our assumptions about the form in which messages are communicated and recognize the *author*ity that is given to certain forms over others. Just because someone can't speak, doesn't mean that they don't have something to say. Just because someone can't read or write, doesn't mean they don't have a story to tell.

Fortunately, it appears that the predominance of written literacy is begin to loose some ground, or rather, other forms of visual literacy are starting to gain credibility. Especially considering the plethora of visual technologies new generations are growing up immersed in today. One filmmaker I interviewed was quick to recognize how as a society we are becoming more literate visually, with images and pictures as opposed to the written word.

> I: Is there something about film and the visual or the audio-visual aspect of it that's that appeals to you?
>
> Steven: Um, I think it's the whole "see it to believe it" thing, because I think that's really important for a lot of people, I think a lot of people are visual and I think that the younger generations growing up are even more visual than ever before.
>
> I: Yeah, in what way?
>
> Steven: Um, well due to computers and cell phones, people are always like looking at stuff, right… I think that people are growing up to be very literate visually.

This brief interaction uncovers that equating vision with knowledge 'seeing is believing' is still a dominant belief in our society. But Steven is also, perhaps, nudging us in the direction that western society and even the global community is heading: toward a growing acceptance of other visual literacies.

As mentioned previously, images, pictures, and videos are travelling across the globe and reaching more people than ever before. With the advent of new technologies such as personal computers, the Internet, smart phones, YouTube etc. there is potential for a cultural turn that relies less on written literacy and instead demands competency in other visual forms. Ideally, one dominant form would not replace the other, but multiple ways of knowing would balance in parallel as equals.

Although there are some that would claim, "we have become a visual society" and already, "the visual has achieved supremacy over the written or spoken word," the prevalence of written literacy (and linguistic communication) remains a critical issue for people with disabilities (Martorella 1997, 511). Until that potential cultural turn is a widely accepted reality, presenting stories via an audio-visual medium is imperative for projects like Project Citizenship chiefly because the majority of people with developmental disabilities cannot read or write. In order to contribute to and have access to their stories, they must be produced in a manner in which people with disabilities can easily partake. If citizenship stories were created in solely written form, many people could never read them, access them, or know them.

When I asked Debbie why the project decided to use art and film as the most common medium to tell citizenship stories, she quickly identified literacy as a leading factor.

I: So why art? Why film? Why this medium?

Debbie: … because people can't read and if we hold power over people by telling stories about their lives in written form, in ways they have no access to, it's an entirely un-collaborative and an oppressive, often, thing to do… It's a universal language. It's accessible to people who are, you know, for people who have really limited cognitive capacity.

In essence, creating a written story would cut many people with disabilities off from the production (and consumption) of their own representation. In a project that seeks inclusion and collaboration, using a form that fundamentally excludes people with cognitive impairments is not only missing the point, it would only work to reinforce the oppressive power relations the project is tasked with dismantling.

Likewise, filmmaker Steven Cresswell acknowledges the importance of a visual medium for a project with people with disabilities:

Steven: Well I'm definitely not against the other mediums, I know every medium has its advantages, but you know with video and pictures, don't people say that "a picture is worth a thousand words?" Like I think that's a really great way to get a message across on a large scale. I think instead of having to explain the connections or the impact these people with disabilities are making, we'll just show you. And I think that's a really great way of getting the message across. Especially when you consider that some people with disabilities aren't the best communicators, a video and pictures is a good way to get the message across.

Early on in this study I was confronted with an issue concerning literacy and

I quickly became aware of how our society's (and particularly academia's) reliance on reading and writing can impact a project involving people with cognitive disabilities. Creating the informed consent and assent forms (see Appendix C), I had to decide how would I obtain consent from a participant with a disability who may or may not be able to read and write. Debbie suggested that I make a video introducing myself and explaining the risks and benefits of participating in this study. This compelling idea flooded me with questions. Would the ethics board approve of an informed consent video? Did I have the time, knowledge and skills to create something like that? How would I distribute it? Would everyone have access to viewing it? How would I obtain and record consent?

It eventually came down to time, and I decided to go with the standard written forms. In most cases the informed consent form was first given to an authorized third-party (parent or guardian) who could explain the study to the individual with a disability and ask them if they wanted to participate. By the time I met with the participants, they had a good understanding of what I was asking them to do, but (as I am told is good ethical practice) I still took the time to read the assent form with them and give them an opportunity to articulate questions and confirm that they understood the risks and benefits of the study.

It was typically an awkward moment when I asked them to sign the form. It had occurred to me that they may not be able to write, and all my participants were able to sign the form with limited assistance, but the decision to approach consent in a written manner has left an uneasy feeling with me. If a major aim of Project Citizenship is to treat people with disabilities as capable adults, as engaged citizens who contribute to society in meaningful ways, why am I first asking their mom and dad if I can speak to them? I realize it is important to ensure that, as researchers, we are respecting their rights. However, it seems counter intuitive to be pushing for

social change on one hand, fighting for people with disabilities to have full citizenship, but on the other hand to be holding them back and only allowing them to exercise their rights (in this case to agree to be in a study, or not) once an 'authorized third-party' says its ok.

I wish I had made time to make an informed consent video. It is a missed opportunity to expand the horizon of acceptable media in academic inquiry and a missed opportunity to set an example of a more inclusive research practice, one that takes the literacy of participants into consideration. This may not be the answer for all cases, but this early hiccup was a valuable eye-opener for me as a novice researcher, which led me to ask insightful questions concerning acceptable forms of literacy within my practice.

For an emancipatory project with people with developmental disabilities, embracing knowledge media other than the written word and using technologies that people with disabilities can actively participate in are critical. Yet making such a declarative statements using printed text appears contradictory. The form of this message ostensibly clashes with the content. Perhaps this thesis shouldn't have been written at all, but filmed, enacted, performed and/or embodied in ways that are more appropriately tuned to a frequency that the people it describes, discusses and represents could successfully receive.

While this chapter focuses predominantly on the visual aspects of the stories made for project citizenship, it is important to recognize that the stories themselves are not solely image based. By design, videos are *audio*-visual we hear them and we listen as much as we watch and witness. In *Audio-Vision: Sound on Screen*, dedicated to the phenomenon of audiovisual illusion, Michel Chion reveals the "expressive and informative value with which a sound enriches a given image" and critiques the notion that meaning "'naturally' comes from what is seen, and is already contained in the image itself" (1994,

5). For Chion, sound "engages the very structuring of vision – by rigorously framing it" (1994, 7).

There is little doubt that images are captivating and vital elements in filmmaking. However, as Chion suggests, viewers should not discount the power of sound, and words in particular, for conveying the meaning expressed in a given film. "Cinema is a vococentric, or more precisely a verbocentric phenomenon… in that it almost always privileges the voice" (Chion 1994, 5).

Although it is not the intent of this chapter to interrogate the audio elements of the stories made for Project Citizenship, it is worth mentioning that at least one citizenship story emphasized sound over sight. At the exhibit, Chris' Story: The Optimist[7] consisted of a wall-mounted CD player and head phones, a photo of himself next to a written copy of the Optimist's Creed, and a plaque on the wall in brail. Audience members could listen to an audio recording that portrayed how Chris experiences his world through sound. With this one example, the benefits of a predominantly visual project are called into question. While privileging sight and visual images over the written word may have benefits for some people with developmental disabilities, visual stories can be equally exclusionary for people with visual impairments as the written word is toward people who cannot read or write.

It is also important to note that most (if not all) citizenship stories contain written language in some way or another. Each film has a standard logo and introduction, which is followed by the story's title: black letters across a white background. Following standard film conventions, the end of each video presents credits listing project sponsors and the video's contributors, again black letters across a white background. Throughout the videos written

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[7] Listen to Chris' story online: http://projectcitizenship.com/the-optimist/

language is used to introduce new characters and describe their relationship to the main character. Some make use of subtitles and others interject with written statements to supplement the images on screen.

As Roland Barthes proclaims, "from the moment of the appearance of the book, the linking of text and image is frequent" and while written literacy may be loosing some ground to other visual epistemologies, it seems to be fulfilling a fundamental position in filmic discourse (1977, 38). Even in non-film based citizenship stories, written text played a significant role. In the center, near the back of the SNAP gallery during Project Citizenship's exhibition last fall, a large photo globe representing the story of a man supported by SKILLS hung nearly four feet from the floor. Interspersed between photographs, were words and phrases meant to complement the images and together construct a coherent story.

Figure 2

As art galleries rely on write-ups, synopsis and biographies to frame the artwork on the walls, it would seem that images rarely stand alone. Words are linked with images and while written text can be oppressive and exclusionary, by nature they are not necessarily exploitative. In fact, many of my informants acknowledged that written words have their place within the context of assisting a disability movement.

When I spoke to Felix about his story and the medium of stories in general, he gave three suggestions: films, radio and books as appropriate methods of delivery. In the end he chooses television as his preferred method, but does not take issue with written forms.

I: Yeah. So you think um film is a good way to get your story out there?

Felix: Ah yeah, film is a great way to get the story out there film or a book or write it on a book or even a film, or even going on to the… news you know on to the news station and going on TV and just sitting there with the anchor people and just sitting there and talking about your story…

I: So do you wanna be on TV one day?

Felix: Um, I would like to be. Um. I don't know I like to maybe cuz I like to film and well I'd like to interview people too, so I wouldn't mind ah maybe getting eventually maybe, maybe down the road I'll get a job as an interviewer at CBC or interviewer at City TV you know… Or just be on the radio you know get my voice heard get out there and get it heard like you know… be heard

I: So if you were on the radio or TV tomorrow, what would you say? What would you wanna talk about?

Felix: I would probably talk about the comic... or the captain community stuff, combination of community and how my, how I started basketball and how... adults with disabilities are not so different and treat people with respect.

Felix clearly understands the message he wants to deliver "adults with disabilities are not so different and treat people with respect," and so long as he 'gets his voice out there' and 'gets heard', he's not concerned with how the message is presented, book, TV, radio etc.

Speaking with Debbie about the benefits of different media, she recounted an incident where being able to write a story was critical for inciting change.

Debbie: Sometimes it's not [oppressive]. Like if I write a really good report or narrative about somebody who's going onto hospital because something terrible has happened to them, they've had a mental illness suddenly come upon them, or this women we work with who suffered a serious stroke like event because of the anti-psychotic medication she was on, ended up in hospital, was treated terribly, has lost the ability to walk probably because they didn't, they dismissed her. Anyway, so sometimes when you can write a really good narrative about somebody that gives people in, like doctors, who don't know the person otherwise, like when you can write in a way that they see as credible

I: Right

Debbie: And that compels, that moves them, you know that isn't [a] clinical dry report, but that's a moving personal story about this person, writing can be affective and you need to be able to do it.

Debbie recognizes that the written word is considered a superior form of knowledge, particularly within institutions power: in this case in hospitals amongst medical professionals. In order to assist people with disabilities in certain situations, allies need to be able to create compelling stories in written form; they need to be able play the game as dictated by those in power. When she says, "you need to be able to do it" she acknowledges that there is a time and place for the written word and that written stories, when well constructed and used in appropriate contexts, can be powerful persuasive tools.

However, a central aim of Project Citizenship is to change the stories we tell and challenge the acceptable methods of delivery within professional discourse. The medical model of assisting of people with disabilities has often been critiqued for its narrow perspective and unquestioning authority, among other glaring oversights. Leavy, in her support of arts based research claims that works of art and performances can reach wider audiences (2009, 14). For Project Citizenship, visual stories and short videos offer an opportunity to combat a medical perspective of disability head on and present a more holistic representation of a human being living with disability, a perspective that is otherwise lacking.

The trouble with a medical perspective is, typically an individual is only identified by a list of impairments and conditions recorded and categorized in written form, which is then filed and locked away in a filing cabinet. The individual has little to no access to it, likely was not consulted in its making, and is compartmentalized and categorized in a manner that the file, full of holes and incomplete information, hardly resembles the human being at all.

Ironically this partial identity, presented in a form that is inaccessible to people with disabilities, holds the most power over the worth of the individual and strongly influences the care and resources a person with disabilities may have access to and thus dictates the life he/she is allowed to lead.

> Ben: We're trying to change the stories we tell, so typically the stories that are told about people with disabilities have been "oh who is this person?" and the first thing you see is well here is what their IQ is, here's what their disability is. Here [are] their behaviours, you know and here's the challenges...

> I: So a medical view

> Ben: Medical view, (nodding) and that's the story of the person... It's a glass half empty perspective, it doesn't help people have good lives. There's nothing to build there. It's looking at people as being sub-human and all that kinda stuff so when we look at somebody and say "what are people like, who are they, what are their interests, what really drives them, what are they passionate about?" Let's build on that and help them contribute that in unique cool ways in the community. Like Andrew with his t-shirt business you know and building on that and Felix with his basketball thing that he started at an elementary school... I think it's helped us... look at what is the more holistic story of a person. Lets focus on that, so its shifted in how we are now doing some of our paperwork about people, that we see at first the real story of the person, then you know the other pieces...

> ... I think the tricky thing or the thing you have to be aware of is a person's medical labels that they don't become the identity of the person you know. The story we tell about them is not just that, which

typically that's then the only story we've told right and… so I think the key thing there is that we don't see people as something we fully, the stories we tell fully humanize and fully celebrate the totality of who somebody is you know so people can have pride in who they are with their disability and all their other qualities as well. I think it is a tricky one that I think we are all still trying to figure out, how do you do that tastefully and respectfully and in a way that's empowering

To be fair, SKILLS has been engaged in a support style known as person centred planning for some time, and while the individual's file may be compiled in primarily written form, the individual is often consulted and collaborates with his/her many allies to create the support he/she needs and desires. In person centred planning, the individual is considered to be at the center and in control of his/her care. This is a big step forward compared to a medical perspective and institutionalized models of support.

As Danielle recognizes, no story will ever represent the totality of a human being:

I: Um. So you do you feel that it shows the real you?

Danielle: Um. You know it its part of me. Like I don't know if it tells everything about me

I: yeah

Danielle: But you know animals is a big part of me. Like I love animals you know

Even with the advancements person centered planning introduces, SKILLS believes that there is room to improve upon the predominant medical view of

disability. Citizenship stories, thus, strive to present a more holistic picture of the people they support, introducing non-medical elements (i.e. a love of animals), into an individual's official record.

Adding citizenship stories to the individual's file inserts vital aspects of the person's life that are not otherwise represented. Moreover, inserting audio-visual accounts in a person's official record means people with disabilities will have access to at least a portion of their file. To ensure people with disabilities have control over aspects of their care and are invited into a dialogue of their own identities, at least part of their file must be produced in a format they can understand, critique and contribute to. For the most part, this means expanding storytelling and record keeping beyond strictly written forms.

Debbie also recounts how stories and visual media in particular have changed her perception on the nature of her work supporting people with disabilities.

> Debbie: The tradition in our field, the mandatory training for people is documentation, "How do I keep good log notes?" and "How do I communicate from this shift to the next?" or "how do I do monthly reports?"

> I: Yeah

> Debbie: You know so, for me I've just… come to understand just how influential and important it can be to use that kind of media [cameras and visual media] to change the way people think about each other and their work together… A really big component of that is holding people accountable for the work that they do, cuz a lot of this work is um, and I'm talking about the staff of course, a lot of this work is people

travelling through the city together as of an eight hour day and you know they come back to, for people living in a group home for example, and they come back and write a few notes about what they did that day and they get buried after seven days… no one sees 'em again and the people, of course, with disabilities who can't read, will never see that and they'll never know how they were represented in that communication… so at of the end of a month I want to be able to go Christine or whoever and say "Show the show me some pictures of what you and Leanne have been doing together" and "let's talk about that and let's talk about how that's enhancing her experience as a valued citizen".

I: So it's also putting their representation into their documentation, like into their file.

Debbie: Exactly, and in a way that they can have way more ownership of that.

In, *Telling New Stories: The Search for Capacity Among People with Severe Handicaps*, John O'Brien and Beth Mont deliver a similar critique of the medical view of people with disabilities by presenting two stories of the same individual, Mr. Davis, side by side. Analyzing the construction, purpose, and consequences of each story along with the assumptions they presuppose, O'Brien and Mont reveal a parallel perspective to Ben and Debbie's, in that stories, which include the individual, focus on capacity, and emphasize collaboration "make the foundation of effective help" (O'Brien 1989, 5).

"Raymond Kilroy, a wise and vigorous advocate for himself and other people with disabilities, gave testimony to the US Senate about his vision for himself and all people with disabilities (Kilroy, 1987). His vision compels attention to new directions for all of us.

We are moving away from emphasizing my needs toward building upon my capacities. We are moving away from providing services to me in some facility toward building bridges with me to communities and neighborhood associations. We are moving away from programing me and other people with disabilities toward empowering us and our families to acquire the support we want. We are moving away from focusing on my deficits to focusing on my competence. We are moving away from specialized disability organizations so that we can develop and sustain relationships with people who will depend upon people like me and upon whom people like me can depend.

To move toward this future we must all learn to listen to, to tell, and to act on new stories, stories whose theme is action to discover capacity" (O'Brien 1989, 6-7).

Twenty-six years after that address, we are still moving toward that future. But with initiatives like Project Citizenship, that hold people with disabilities at the centre, and that rewrite (re-right) the stories that we are told about disability, in forms that are inclusive and accessible, that future appears all the more attainable.

Chapter 4 - Objects, Vehicles and Inspiration

"The concept of culture I espouse… is essentially a semiotic one. Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning".

~ Clifford Geertz (1973, 5)

At the beginning of this research endeavor I set out to uncover what digital stories have come to mean for various people involved in Project Citizenship: authors/creators, subjects/stars of the stories, and audience members/viewers. Following Geertz' understanding of culture I went looking for a 'thick description', a rich interpretation that lies beyond simple behaviours and surface activities. This path has led me down multiple paths from where I could draw many conclusions. For example, to leaders at the SKILLS Society the stories signify education, hope and acts of creation. For creators and people with disabilities they mean happiness and pride. To all, stories evoke a tremendous sense of accomplishment.

However, held together under a theme of 'transformation', there are three loosely associated findings that I feel are worthy of more in depth analysis and despite meaning many things to many people, this chapter will focus on stories as objects for memory and human connection, vehicles of agency and stories as inspiration. The majority of this chapter explores a controversial critique of inspirational narratives and reveals the entangled complications that surface when stories have come to signify inspiration.

<u>Objects</u>

Throughout this research I have found that in certain moments stories take on a physical form. While yes they exist as short videos online, which are somewhat tangible entities, at times they manifest themselves by means of other physical objects. During two of my interviews, people got up to get *things* to share with me. They would bring me photographs or newsletters related to their story or seemingly random objects that on first glance appeared to have little significance.

> Debbie: When I want to tell stories to people I use pictures often you know… and my artifacts, like this is something (goes to her desk draw to pull out an object) I found this when I was, maybe I brought it to a Think Tank one time, have you seen this?

> I: Nooo (excited)

> Debbie: This is really, I found this when I was a kid living in Edmonton, in a hermit shack in the ravine

> I: Yeah (smiling)

> Debbie: And I spent a lot, when I was eight maybe

> I: So you weren't living in a hermit shack you were

> Debbie: No, my friend's father took us down to the ravine and I found it

> I: So cool!

Debbie: And it was in there and you know. These things yeah, so it's a long story, but that's a thing I've had like all my life, pretty much

I: It's like a touchstone (I'm holding this small metal object that has had two pennies squished into it, one face up the other face down. I recall that the date on one of them is 1958).

Debbie: It's like a touchstone

I: Yeah (I pass it back to her)

Debbie: It's a talisman kina thing

I: Umm

Debbie: I always wondered, it's probably given me lead poisoning over the years cuz I would pick at it with pins

I: (laughing)

Debbie: and shine it up and try to melt it in my mother's frying pan…

In this discussion Debbie and I are involved in a kind of meta-dialogue about the power of objects and how they relate to stories. But at the same time Debbie is telling me a story of her childhood, and through this object she is sharing details of her personal life and inadvertently revealing her passion for collecting. It's as though this object is a physical extension of the story she wants to share and by merely presenting it, the thing itself, like a talisman, conjures up memories, past experiences and previous tellings of the same story.

Janet Hoskins remarks, "in a way the object becomes a prop, a storytelling device, and also a mnemonic for certain experiences" (1998, 4). While these story objects certainly trigger memories, they can also quickly establish a sense of trust between people, which eases communication and directly facilitates interpersonal connection.

Holding my informants personal objects in my hands, I felt a growing sense of intimacy between my storytellers and myself. I was humbled by their willingness to openly share such personal items and surprised by the ease with which these objects allowed intimate details to be revealed. More than possessing significance for the individual, the objects act as entry points to conversation and foster new relationships.

While these objects were invaluable to me as anthropologist aiming to establish rapport, Debbie reveals how the created digital stories are objects that can assist people with developmental disabilities to engage with their communities and create meaningful relationships.

> Debbie: ... all these kind of objects, and for me just intuitively, it just makes sense and people with disabilities who can't talk who cant write who are you know have problems remembering, problems relating to people sometimes you know things that get in the way like social behaviours that get in the way of them being perceived positively... What a nice tool to give them.

For people with disabilities having a story to share is invaluable for connecting with other people. Whether it is a secondary object or the story as the object itself, they are tools for people with disabilities which they can use help them express who there are, share their self-worth, and at the very least establish a dialogue with people who might otherwise dismiss them. As discussed previously, stories can help people with disabilities remember past

events and interactions with other people, but these stories also help build new friendships and strengthen existing ones.

When Wes and I were going over the assent form before our interview started, I asked him if he had a copy of his story. He said that he had bits of it and he got up to go get something. He came back with a newsletter from Little Bits that had a full page write up about his story and Project Citizenship. He told me that he has shared this with many people and others have read it independently and called him to talk about it. One person was his doctor, which he brought up again during the interview.

> I: That's great. So do you think your life is any different now that you've had this story and

> Wes: Oh yeah

> I: Yeah? How is it different?

> Wes: My life, I feel like… well it kinda changed my life… I'm proud of myself and what I went through with the two girls[8] and you know after it was all done I told everybody how famous I was and they… yup. I even told my family doctor how famous I was (laughs)

> I: Really?

> Wes: Yeah (laughs) He gotta big joke out of it

Wes has a preexisting professional relationship with his doctor, and while this story might not significantly alter their relationship, the fact that his

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[8] 'Two girls' refers to the two CSL students who helped document Wes' story.

doctor read the story independently and had a conversation about it with Wes demonstrates that through this story object Wes was able to share a meaningful (non-medical) part of his life with another person and establish, momentarily, a level of intimacy that might otherwise never exist. In this context what Wes calls fame, can be read as the pride he feels from external recognition.

Of course I have not spoken with Wes' doctor to explore the depth of their relationship nor the impact this story and interaction has had for him. However, as a result of sharing his story, Wes feels proud and a little bit famous. These stories, as sharable objects, become tools for fostering personal interactions and can further engage people with disabilities in their communities. Its an almost cyclical processes whereby people are involved in their community in some way, a story is made about their activities and engagement, and then this story can be passed around and shared with new groups of people where opportunities for further engagement are forged.

At another point during our interaction, Wes got up and came back with a picture of him that Little Bits had given him as a present on the last day of the season last year. It's a framed photograph of him with a horse he leads named Rooster and along the bottom, all of his co-workers have signed it. Like the newsletter this photograph is another touchstone, which Wes uses to mediate the telling of his story. Like a portal, it works in two directions. On one side it serves as a reminder of his friendships and how he is valued at work and on the other side sharing this object with me, this object presents an opportunity for us to get to know each other and make a connection.

Figure 3

Wes: And I joked, I was joking around with them yes, last year and said, "I think I'm going retire" and they said "No, you're not going to retire"

I: (laughs)

Wes: (Laughing) "we want you"

I: (laughs)

Wes: (Laughing) "You're such a good worker"

I: Awe

Wes: So, that's pretty well, what, what I do out there and

I: And this picture, they gave this to you the last day you worked?

Wes: Yeah

Looking at his photograph and it's many signatures, Wes knows that he is valued. By sharing it with me, I know that he is valued too.

Vehicles

More than static objects, on occasion my interviewees have revealed how stories have come to serve as vehicles, as transformative bodies that manifest new opportunities. In one example, Debbie explains how having citizenship stories allowed a few people SKILLS supports to act as mentors and present in front of a classroom as part of Project Citizenship's Action Hall.

Debbie: One of the really cool things is they have become vehicles for people who are the stars of the film to be guest speakers and instructors in the Action Hall... Daniel and his Dad, step-Dad came to the Action Hall and showed his film. Of course Daniel can't talk, but he was riveted as his step-Dad spoke.

I: Wow

Debbie: And explained... how that story emerged and the importance of it and so on.

I: Yeah

Debbie: As did Jason, and the Captain Community story. He came with Jack and they spoke to the class and so it's a vehicle to have this valued role as kinda cool citizen, engaged citizen, teacher, mentor.

Likewise, at the opening gala for Project Citizenship's art exhibition, many people with disabilities took on expert roles discussing their stories with audience members at the SNAP gallery. This prestigious celebrity role was an exciting opportunity to introduce themselves to new people. As Felix expresses,

Felix: I thought it was awesome, it was great, it had a great turn out, I thought it was great, a lot of people showed up to see a lot of the films, these stories that were there… people talked to me and liked my story I even talked to some strangers I didn't even know, saying "so check out my story, I made this video" you know… They asked about it, they checked it out…

I: And how did that make you feel?

Felix: It made me feel great, you know just to get out there and just talk to people and say you know 'this is my story, this is what I do, this is like, I volunteer with kids and do basketball, this is my story, check it out man'…

I: So do you have any special memory of the gala session?

Felix: Hmmmm not really, just to the just… I got my picture taken with the mayor cuz the mayor was there making a speech.

Like vehicles, citizenship stories are opening up new avenues and taking people with disabilities on a journey they might not otherwise traverse and with people they might not otherwise meet.

While these opportunities are still within the context of the project, some stories have lead the stars of the videos to horizons beyond the realm of Project Citizenship and the SKILLS Society. In Jason's case, his Captain Community story has taken him to new places and helped him connect him with a much larger community.[9]

Jason's video can be divided into two parts, the first section is told in the form of a comic and was first published in print by S.O.S Children's Safety Magazine. Digitally redone with movement and voiceovers, through the video comic we learn of Jason's neighborhood vigilantism. Represented as a superhero named Captain Community, Jason intercepts a burglar breaking into his friends' home and contains him until the police arrive.

In the second part of the video we see how having a story to share takes Jason down a path he never expected. About half way though the video we see the real Jason sitting in a conference room at the Edmonton Police Service West Division. After reporting his stolen bike, Jason told the police officers how he was a superhero and showed them the comic published in S.O.S magazine. Inspired by his commitment to the community and for helping keep the city streets safe for his friends and neighbors, the West Division felt compelled to reward Jason.

Near the end of the video, we watch Jason's story quite literally transform into a vehicle. What started out as a man protecting his friends turns into a shiny red bicycle presented to him by the Edmonton Police and their friends

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[9] Watch Jason's Story Captain Community online:
http://projectcitizenship.com/captain-community

at United Cycle. In return, both organizations are given a foam-mounted poster of Jason's comic.

In this short video audience members can see how having a story to share has taken Jason in new directions and expanded his community connections. The video was featured at Project Citizenship's opening gala where it was seen by the mayor of Edmonton, Stephen Mandel, the Alberta Government's Associate Minister of Services for Persons with Disabilities, Frank Oberle along with three hundred and fifty members of the general public. In the weeks before the gala, his story was also picked up and shared in the Edmonton Journal. Only time will tell where Jason's story will take him next.

In these examples I have tried to demonstrate how the stories made for Project Citizenship have become vehicles. They signify new directions, open highways and movement along channels that people with disabilities rarely travel. Whether it is Daniel presenting his story beside his step-Dad as a leader in front of a group of students, Felix promoting his video at a gala, or Jason honoured by police, these stories are vehicles for new experiences and new relationships.

Of course not all stories have had such profound implications. While all stories have the potential to spark new opportunities and connections, some simply have not realized the same transformative potential as others. When I spoke with Danielle and Felix about their stories both indicated that the videos did not dramatically changes their lives in any way.

Danielle:

> I: That's so great. Um. So do you think your life is any different now that you have made this story?

Danielle: Um, I mean no I just kinda carry on, like I know my video's out there and like pretty soon they'll have it um available for anyone to look at which I'm absolutely fine with it.

Felix:

I: So has your life changed at all now that you have this story, or are you, you're pretty used to having stories in your life

Felix: Yeah yeah

I: And films about you, but has your basketball or this other one, impacted your life at all?

Felix: Not really

I: Not Really?

Felix: No

I: No?

Felix: I don't have anything to say (laughs)

I: (Laughing)

Felix: Nothing has changed

While citizenship stories are vehicles and do expose people with disabilities to new experiences, it is difficult to say if these stories will have a lasting or life altering affect on the people they represent. Even though Felix discusses

how the gala was a new and exciting experience for him and provided an opportunity to share his stories with others, this event and his story have not made a significant impression on his day-to-day life.

One filmmaker also noted that he did not expect the stories to have groundbreaking effects, but still he recognizes the importance of starting somewhere and initiating the action so that momentum can build.

> Steven: Well to be honest, I don't expect that these stories are going to revolutionize the world, but, you know you gotta start somewhere, right? If nobody's do anything then nothing's gonna happen.

Why some stories are more successful at creating new opportunities for community engagement than others is not fully understood. I can only assume that in any given case there are multiple forces at play. Some stories are simply better than others. Some strike a cord with an audience member and call individuals to action, like the police officer in Jason's story. Not all stories get the same exposure. Danielle's story was made after the art exhibition and was not on display at the SNAP gallery.

Some people with disabilities, like Felix, have many stories and with many stories comes many opportunities. Individuals in this situation may have less desire to seek out new experiences and personal connection. Others are more tied up in a complex web of physical, mental, social and political factors that stories alone may not be able to overcome. One citizenship story, a painting depicting a young woman's transformation from hospitalization to freedom, was not displayed at the SNAP gallery because the individual's guardian would not allow it. More research could be done to examine the socio-political factors that influence stories transformative potential.

Looking more closely at another site at which meaning is made, the following section explores the impact citizenship stories have had on the stories' filmmakers and creators. Although both filmmakers I interviewed indicated that making the stories was "just a job," or "just means another story," Steven expressed how his job evolved and the stories took on deeper meaning as he connected with more people.

I: So as a filmmaker, as a creator um what do these stories mean to you?

Steven: Um. Well. What it meant to me, it kinda evolved cuz you know at first really, it was just, it was just a job

I: Yeah

Steven: But as I got to know these people, you know, a lot of them I started to care about them… I wanted their story to be as good as possible and I wanted it to be as good as possible for them. You know when I was going and seeing all these people with disabilities…people with severe disabilities, made me realize that these stories are even more important than I thought they were at the start.

I: Yeah

Steven: So their importance to me increased and when I realized how much work there is to be done, and how marginalized people with disabilities are… so for me making these stories meant that it was going to bring joy to people with disabilities it was going to bring joy to their family and hopefully educate the public a little bit and make some change.

For Steven, what began as a summer job transformed into social action. As he began to understand the cause and develop relationships with people and witness their social condition, he was compelled to take action in whatever way he could. He worked at making the best stories possible, not for himself, but for the people he was documenting. Going to work transformed into a deeper compassion for the suffering of others and spreading joy replaced mundane employment. Challenging social perception of disability through story has become a chief concern of Steven's, a priority that has evolved through his involvement with the project.

Steven is not the only creator who has been inspired to be part of the change through his/her involvement with Project Citizenship. While I wasn't able to interview students who created citizenship stories, there is a video titled "UofA Student Stories – Their Thoughts on Project Citizenship"[10] which provides insight into the student experience. To be clear, this video is about Project Citizenship's Action Hall and does not specifically gather feedback from students who were solely involved in the creation of citizenship stories.

However, in this video we hear the creator of Danielle's story, Trisha, discuss what she has learned through her involvement in the project and express the impact this experience has had on her perception of people with disabilities.

> Trisha: The best experience I had was working one on one with Danielle. Being in an environment where she's really just radiant, enjoying what she does and passionate in contributing to the society was just really awesome to see.

While Trisha enjoyed working with and getting to know Danielle, she also explains how after speaking with Danielle's case-worker she started to

[10] Watch UofA Student Stories online: http://projectcitizenship.com/u-of-a-student-thoughts-on-project-citizenship

understand the limited and limiting perspective many people have regarding the capacities people with disabilities have and the societal contributions they are making. Through her experience in the Action Hall and by creating a story with Danielle, Trisha was inspired to be part of the change.

> Trisha: Eye-opening experience for me… society has these stigmas of people with disabilities and it makes me think, what can I do as an individual to help change these things, um and I think what we need to start doing is looking at the talents and the gifts these individuals have instead of thinking about the stigma.

Through this video we can infer that the opinions offered by the students who took part in the Action Hall would be similar to those involved in story making. Recognizing that this video has been edited with a particular agenda in support of the project, none-the-less it would appear that Project Citizenship has had significant impact on how students perceive people with disabilities. Working closely with Rihanna, Kelsey discovered that they share common interests like animals and artwork and remarks that one of the most impactful insights she made from her experience was the "realization that these people are a lot like I am".

Directly referencing citizenship stories, Zahin discusses how watching videos that emphasize contribution over deficiency contributed to the most significant lesson she learned.

> Zahin: The most important thing that I learned from being a part of this project was how they were able to bring out the passions of people with disabilities and showcase their stories of engagement in the community to the rest of us, and how they portrayed people with disabilities beyond their vulnerability.

Again, it is difficult to say how impactful and transformative these experiences will be for students in the long run and it is not known how much the Action Hall might contribute to this change over and above being involved in the creation of citizenship stories. More research could explore the Action Hall component of Project Citizenship and how it contributes to the project's overarching goals: creating opportunities for community engagement and challenging social perception of disability. However, examining this small collection of data, it is evident that these stories are behaving like vehicles for students as well, they are taking them in new directions, introducing them to people they might not otherwise meet, and creating space where change is possible.

Inspiration

"The power of disability arts and culture is nothing short of the elusive making of truths by disabled people that challenge non-disabled representations, taunt each other, play with each other: representations of people with disabilities as tragic, pitiful, whiney, monstrous, devious, or heroically inspirational come back like a bird that slips through your fingers, only to reappear in shapes, forms, unexpected bodies and voices that rejoice with collective sensibilities, flesh bone and blood, daring to stare back, to create and participate in a movement that cannot be contained to any one particular moment or series of events…"

~ Leslie G. Roman (2009, 1)

The stories made for project Citizenship are undoubtedly 'inspirational' and have come to serve as a beacon of inspiration for many people involved in Project Citizenship. In particular, the leaders at SKILLS and audience members frequently used the word 'inspiring' to convey what citizenship stories have come to mean for them.

Audience members have used the term in response to more than one survey question:

1.   Using between 10 and 25 words, what are your initial thoughts, feelings, and reactions to Project Citizenship's gallery exhibit?

A2: I feel *inspired* by the stories as well as their makers. Knowing people spent time helping others share their stories is something I had never thought about.

2.   Are their any stories in particular that stand out for you? If so, how come?

A1: Zim Zam enterprises! The very determination and resourcefulness was *inspiring* to me.

3.   Has anything you saw or heard at the gallery influenced your perception of people with disabilities? If so, in what ways?

A2: There were stories of meaningful contribution; not quaint descriptions of how people with disabilities can also "help out". I found this *inspiring*.

Ben also overheard audience members talking about the stories:

Ben: That was a lot of the comments I overheard people saying, "Oh this is so *inspiring*, this is really shifting my thinking. This is really interesting, *inspiring*"

I: And that you heard at the gallery or since then or?

Ben: I heard that at the gallery, people just talking and afterwards, people talking about it. Um. Key word there was just really "*inspiring*"

Beyond signifying inspiration for audience members, Ben himself remarks how the stories are inspiring him to contribute to society in more meaningful ways.

Ben: In some ways they kinda make me think, 'oh man, I am learning a lot from people with disabilities and the cool citizenship things they are doing' and 'how I can be doing a lot more in my life?' So in a lot of ways they kinda make this, you know, as somebody who supposedly doesn't have a disability, it makes me think, um 'wow I could be doing a lot more'. Look at what these people are doing and how *inspiring* it is. So they kind of *inspire* you to want to be better in a way.

Through speaking with the leaders at SKILLS who pioneered Project Citizenship, I have learned that one of the major tools they rely on to incite change both within the organization and the larger public community, is 'inspiration'. In our interview, Ben cited Michael Kendrick, a consultant in the areas of leadership and emerging developments in the fields of disability, mental health and aging, who promotes the benefits of using inspiration in these areas. The quote Ben led me to is as follows:

"What we have also learnt about is the power and necessity of inspiration. People may often worry unduly about laws, regulations, money, systems and technology when what may make the most crucial difference might ultimately be whether people act in inspired ways. Without inspiration you will probably not move mountains or make any significant difference because the vision and conviction that inspiration brings will be missing. Each of us typically has the capacity to become

inspired because a significant part of us is the spirit that moves us. Inspiration is a bit like water. If we do not have water, after a while we will die. Inspiration is the water of life. It is that which enlivens us, it gives us life and causes us to shift and expand in creative ways" (Kendrick 2005).

Within the context of Project Citizenship the term 'inspiration', has a positive and desirable connotation as it is viewed as powerful emotion for influencing others to perceive, think and act differently. It has the power to 'move mountains' and creatively expand social perception of disability. Taken as fundamental to life itself, a necessity like water, the project perceives the vital role inspiration has to play in creating stories that depict people with disabilities as equal and valuable citizens.

However, among disability scholars the role of 'inspiration' and 'inspirational narratives' has been largely contested. From the perspective of many working in the realm of Disability Studies, inspirational narratives are considered to contribute to the marginalization and discrimination of people with disabilities. Examining how people with disabilities are portrayed in certain films and news media, disability activist John Kelly claims, "disability inspiration is a form of propaganda that glosses over oppression while simultaneously reassuring normals about the superiority of their ways" (2003).

Examining the critique of inspiration by leading scholars in the field, 'inspirational stories' appears to be ensnared within three major arguments, which are deeply intertwined and implicate one another in a complex, knotted web. Firstly, scholars contend that inspirational stories that celebrate the achievements of people with disabilities do so according to an able-bodied standard.

"Paraplegic Masha Malikina of Atlanta became an inspirational celebrity last June for wanting to "walk" across the stage to receive her high school diploma. After the school principal denied her request, a local radio station organized a grass-roots campaign that led to her having her own special ceremony, culminating in her moving with full leg braces and a walker to the podium, where, exhilarated, she received a standing ovation from the crowd. Would such accolades have greeted a different scenario, one in which scores of Malikina's friends joined her in wheelchairs at graduation to both show their solidarity with her and revel in the fun of using a wheelchair? No; the tributes must go only one way -- and they are nonstop" (Kelly 2003).

In this example, we judge Malikina's success by her ability to perform in an able- bodied activity and not our failure as a society for not accepting Malikina for who she is on her own terms. Kelly further critiques inspirational narratives

"for their underlying assumption that we are as a group inferior to normals, thereby making remarkable our smallest achievement. These stories… not only deny group oppression by individualizing disability, but reinforce that oppression by seeming to blame the vast majority of disabled people for *not* achieving" (2003).

Reiterating inspirational narratives and valorizing small achievements of people with disabilities who can measure up to able-bodied standards, to some extent reinforces existing oppressive power structures and puts unrealistic expectations on people with disabilities who are not contributing (and who may have no interest in contributing) to a hegemonic ideology that measures the value of a disabled person's achievements against an abelist rubric.

In *The Right Not to Work: Power and Disability*, Taylor questions if fighting for inclusion in the workforce, an ablest system that follows capitalist standards of measuring self-worth, is the desired direction for the disability movement.

> "Disabled people are brought up with the same cultural ideals and ambitions and dreams as their able-bodied counterparts; we too are indoctrinated to fetishize work and romanticize career and to see the performance of wage labor as the ultimate freedom. And yet, for the most part, we are denied access to this fantasy; many of us live on government aid or family support or even charity… Shouldn't we, of all groups, recognize that it is not work that would liberate us (especially not menial labor made accessible or greeting customers at Wal-Marts across America), but the right to not work and be proud of it?... I want to make clear that I am not saying people should stop fighting for equal rights in our current system, but that we should simultaneously think beyond the system in place… I remain unconvinced that fighting for equality within the current system (that is, to some extent, the right to be part of the exploiter class as opposed to being part of the exploited) is the ultimate ideal worth fighting for" (2004).

What Kelly and Taylor find troublesome with inspirational stories that depict the contributions and successes of people with disabilities, is that they often send the message that people with disabilities are worthy, equal citizens because they can demonstrate capacities (i.e. gain employment), on able-bodied terms. It is a red herring that can distract people with disabilities and able-bodied persons alike from addressing the real issue. "Is the goal to be "mainstreamed" into our current society or to change society?" (Taylor 2004).

Likewise, Longmore suggests:

"Most of us who have disabilities hate the word "inspiring." We hate being told we are "inspirations." We know it is usually a way of devaluing us as heroic oddities. It is a weapon to blame handicapped people who have not proved their worth by cheerfully 'overcoming' their disabilities. It is a way of distracting attention from the reality of prejudice and discrimination and inaccessibility that thwart the lives of millions of us" (2003, 130).

The second argument against inspirational stories is that they often depict people with disabilities who not only measure up, but surpass normative able-bodied expectations. Investigating popular stories and images concerning disability throughout time, Fiedler argues that the prevalence of depicting people with disabilities as super-human, surmounting unbeatable odds, and triumphing over struggles only reinforces the 'othering' of people with disabilities. "Such ersatz sagas of heroic "gimps," then, merely turn upside down rather than dissolve the sense of immitigable difference which lies at the root of our troubled response to the disabled, by making them seem super- rather than sub-human" (Fiedler 1982, 61).

For Fiedler, portraying people with disabilities as super-human in stories reinforces their sub-human status in reality. In a quest for equality and dissolution of difference, inspirational super-human stories impede the cause, as they, by design, represent the other side of the abelist coin. Therefore, presenting people with disabilities overcoming insurmountable difficulty and achieving beyond expectations of the able-bodied population can be viewed as antithetical to the disability movement.

Chrisman claims,

"in disability studies, the inspirational narrative has become intrinsically bound to the narrative of overcoming: that is, the idea that

one can take sole responsibility for conquering one's disability and its attendant challenges. The belief that a person with a disability can and should pull oneself up by the bootstraps despite overwhelming odds is an impediment to understanding the sociocultural barriers that people with any given disability may face" (2011, 173).

With this statement Chrisman leads us into the third argument: inspirational narratives are problematic because they fail to address the social construction of disability. "Herein lies the problem... it is not just that these narratives sentimentalize the experiences of people with disabilities, but they lack perspective on the more pervasive issues regarding disability... [they] fail to address the sociocultural construction of disability, the real barriers that stand in the way of people with disabilities" (2011, 176).

Eli Clare also critiques inspirational 'supercrip' stories for failing to recognize disability as socially constructed:

"Supercrip stories never focus on the conditions that make it so difficult for people with Down's to have romantic partners, for blind people to have adventures, for disabled kids to play sports. I don't mean medical conditions. I mean material, social, legal conditions, I mean lack of access. Lack of employment, lack of education, lack of personal attendant services. I mean stereotypes and attitudes. I mean oppression, the dominant story about disability should be about ableism, not the inspirational supercrip crap, the believe-it-or-not disability story" (1999 2-3).

For Chrisman and Clare, inspirational stories are problematic because they depict people with disabilities overcoming their individual physical or cognitive impairments while ignoring the larger socio-political barriers that

prevent people with disabilities from living as equal citizens in our communities.

While the critique of inspirational narratives brings to light an important and valuable debate in Disability Studies, I find myself aligning with Chrisman who, despite the validity of opposing arguments, believes that "not all experiences of inspiration are infused with this reductive notion of overcoming"… and finds it "difficult not to find redeeming qualities in inspiration or inspirational narratives" (2011, 173 & 175).

Turning to the context of Project Citizenship, some stories could be read as playing into the inspirational tropes some scholars find contentious. Certainly some citizenship stories could be taken as attempts to make mundane tasks seem like remarkable achievements. Many stories tell tales of individuals going to work, which as Taylor claims, feed into the capitalist ideal of self-worth. Jason's Captain Community Story intentionally portrays Jason as superhuman. In Danielle's story, overcoming her fear of large dogs can be read as a metaphor for her overcoming her disability to an extent that allows her to volunteer in an able-bodied context at the Humane Society.

Predicating the project on such a conflicted term as 'inspiration' necessarily implicates Project Citizenship in this controversial debate and as such it is caught up in the dangers as much as the benefits such a term affords. However, despite the criticism, there are some areas where the stories made for Project Citizenship may gain some ground. First, there seems to be a semantic difference between the way the project is using the term and the way scholars who critique 'inspiration' appear to dismantle it.

"To "inspire" literally means to "breathe into" another person -- "to infuse an animating, quickening, or exalting influence into"" (Kelly 2003). But by definition 'inspiration' does not dictate the particular emotions, behavior or

influences the receiver is meant to inhale. There are many kinds of narratives about disability and while some stories certainly inspire pity, fear, sympathy and shallow sentiment, in their construction and the manner they are presented other stories can also inspire a shift in attitudes, new ways of thinking and desire for social change.

The trouble with the term inspiration appears, at least in part, to be linguistic. Used by those who label it as catering to ablest agendas tend to align the term more closely with a connotation of sentimentality, simplification or frivolity. Stories that simplify the barriers people with disabilities face, present one-dimensional simplistic characters, or trivialize achievements are certainly problematic. However the way audience members and leaders at SKILLS position the term, associates inspiration with a call to action: citizenship stories inspire new perspectives and change in behaviours.

Revisiting the quotes from SKILLS leaders and audience members above, we can see how the term inspiration is nestled within a context of perceptual transformation as opposed to mere sentiment.

Audience members:

> 1.   Using between 10 and 25 words, what are your initial thoughts, feelings, and reactions to Project Citizenship's gallery exhibit?

> A2: I feel inspired by the stories as well as their makers. Knowing people spent time helping others share their stories *is something I had never thought about.*

> 3.   Has anything you saw or heard at the gallery *influenced your perception* of people with disabilities? If so, in what ways?

A2: *There were stories of meaningful contribution; not quaint descriptions* of how people with disabilities can also "help out". I found this inspiring.

Ben also overheard audience members talking about how the stories where challenging how people are thinking about disability:

Ben: That was a lot of he comments I overheard people saying, "Oh this is so inspiring, *this is really shifting my thinking.* This is really interesting, inspiring"

The shift in meaning is subtle, but with these examples, we can see how audience members link inspiration with a change in perception: "I feel inspired… something I had never thought about" or "this is so inspiring, this is really shifting my thinking." One audience member even calls out how these stories were inspiring because "there were stories of meaningful contribution; not quaint descriptions." For the audience, the project is not merely creating 'inspirational stories', but inspiring them to think differently about people with disabilities and their place in society.

Beyond inspiring new ways of thinking, Ben recounts how the stories have inspired him to act.

Ben: In some ways they kinda make me think, 'oh man, I am learning a lot from people with disabilities and they cool citizenship things they are doing' and *'how I can be doing a lot more in my life'* So in a lot of ways they kinda make this, you know, as somebody who supposedly doesn't have a disability, it makes me think, um *'wow I could be doing a lot more'.* Look at what these people are doing and how inspiring it is. So they kind of *inspire you to want to be better* in a way.

Presenting the power (or at least potential) to influence perception and call to action, it is hard to believe that there is no room for inspirational stories within the disability movement. Unfortunately the research presented here does not put me in a position to offer solutions. However, to alleviate the semantic tension apparent within the term, words like 'transformative' or 'transformational' might be helpful, as they contain a connotation of movement, action and change. As Debbie commented, Project Citizenship is "a way of having some kind of body of work that is accessible and intriguing and inspiring to the more general public... about the world and who belongs in it." More than inspiring, the project is about changing public perception and transforming our communities into inclusive spaces.

Additionally, despite the critique on portraying small achievements, there are benefits to presenting people with disabilities accomplishing mundane tasks. In their of examination of disability narratives throughout various historical periods, Mitchel and Snyder claim that "most basic to the identification of character through disability is the way in which physical and cognitive differences have been narrated as alien to the normal course of human affairs. To represent disability is to engage oneself in an encounter with that which is believed to be off the map of "recognizable" human experiences" (2003, 5).

By depicting everyday tasks and mundane achievements, without undue valorization, citizenship stories work to re-humanize people with disabilities. Portrayed in some of the most recognizable human experiences: at work, with family and friends, participating in sports, hobbies etc. these inspirational stories stand in contrast to predominant ablest disability narratives.

Another factor that may influence the debate on the value of inspirational stories is the type of disabilities those represented in the stories may have. As Mitchel and Snyder contend, within the disability movement there are elemental differences for (and hierarchical power relations between) people with physical impairments and those with developmental, cognitive, or psychological disabilities.

> "From the segregation of special education classrooms to the systematic murder of people with cognitive disabilities in Nazi Germany, the fate of people with physical disabilities has often depended on their ability to distance themselves from their cognitively disabled peers. This internalized oppression has resulted from institutionally enforced hierarchies of disability" (2003, 3).

People with developmental disabilities experience their disability, and particularly the social aspects of their disability, in ways that are fundamentally different from people with physical impairments. Therefore, it is worth considering the extent to which the critique of inspirational stories fits within the context of a project engaged primarily with people with developmental disabilities.

Chrisman also notes that a critique on inspirational stories may not adequately address all persons who identify with having a disability. "Part of the cautious or dismissive reaction to the inspirational narratives rests, I believe, on the fact that those narratives upheld as inspirational and overcoming are typically narratives of physical, visible disabilities" (2011, 180).

This is not to suggest that people with developmental disabilities should be less concerned with producing stories that play into ablest hegemony. But perhaps researchers should be asking questions that take the physical versus

cognitive distinction into consideration. New research questions could include: what conditions exist that may provoke people with developmental disabilities to address the issue on inspiration from different perspectives? Are there other higher priority barriers that need attention before a dialogue on normative power structures can be raised? How difficult is it to express what is at stake within an ablest, capitalist fantasy with people who, at the very least, have difficulties with memory and communication? Do inspirational stories have something to offer people with developmental disabilities that the current conversation has missed? Again Chrisman posits, "the inspirational narratives most often critiqued in disability studies, are less likely to focus on mental illness or psychiatric disabilities as inspirational. So I question, what might inspirational narratives mean to them?" (2011, 181).

Many arguments against inspirational stories contend that they fail to recognize the social barriers people with disabilities face (Chrisman 2011, Clare 1999). Citizenship stories may not directly discuss ableism, that is, they don't come right out and say, "this is about rights." However, they do address the social construction of disability by challenging dominant attitudes and stereotypes. Depicting people with developmental disabilities contributing to society, engaging in their communities, and exercising the same rights and freedoms as able-bodied persons contradicts the prevailing assumption that people with disabilities are burdensome and have little (or nothing) of value to contribute.

Furthermore, watching individuals stand up to this misinterpretation reveals that the barriers people with disabilities face are not solely physical or medical conditions but consist of larger social constraints. Witnessing people with developmental disabilities participate in ways largely considered to be impossible, demonstrates that an individual's limitations are not exclusively personal. To borrow from Chrisman again, these stories "conflate the

personal and the political, a linkage prominent (and even necessary) in all rights movements" (2011, 178).

Similarly, in his discussion of Daniel Day-Lewis' character Christy Brown, in the film *My Left Foot,* Paul Longmore expresses the importance of heroes in the disability movement and how inspiring stories can expose disability as socially constructed:

> "Christy Brown, difficult and dangerous as he is... embodies the consciousness of a generation of people with disabilities who assert that for the overwhelming majority of us prejudice is a far greater problem that any impairment, discrimination is a bigger obstacle than disability. He reflects our demands for full human dignity, self-determination, and equal access to society and life. Christy Brown is a hero of our struggle. We will be inspired by his glorious disabled rage" (Longmore 2003, 130).

Ben Weinlick also recognizes the importance of seeing people with disabilities overcome struggles. In his experience stories of 'overcoming' can be powerful change agents and can open up spaces for interpersonal engagement. "When you see somebody's story and you see the struggles and you see the triumphs and all that, that hits you in a much more um, intense way... that can actually have the possibility of maybe chang[ing] your perspective". Furthermore, there are countless inspirational stories about able-bodied people overcoming their struggles. Denying people with disabilities the right to participate in a particular genre could easily be read as ablest and discriminatory.

Ben has also witnessed how showing triumphs has opened up opportunities for his brother to make meaningful connections in his community, "they're seeing his cool contribution and how unique that is and how he's triumphed

over all these struggles so then it created opportunities for him to be invited and feel a sense of belonging and be part of things".

"Sometimes…the word "inspiring" fits. People with disabilities do need heroes, not uncomplaining overcomers, but real disabled heroes who fight bias and battle for control of their lives and insist that they will make their mark on the world" (Longmore 2003, 130). Despite the arguments against using inspirational stories and their problematic tropes, there are times when it is important to show triumphs, success, superheroes, and mundane achievements.

To be sure, Project Citizenship is undoubtedly implicated in the 'inspiration' debate. While, this research does not offer solutions, It raises some important questions about the role of inspiration and inspiring narratives within disability discourse. On the one hand, inspiring narratives can be seen as catering to existing normative and ablest constructions of what people with disabilities ought to be achieving in order to be considered equal. Yet, on the other hand, they can be seen as transformative and empowering, imploring audiences to question assumptions and shift their perspectives concerning people with disabilities and their contributions to society as equal citizens.

Using inspirational narratives, then, is about balance, about negotiating detriments and benefits in creative ways that correspond with the given agenda and the individuals involved. So long as the fissures and pitfalls are illuminated, those interested in recuperating inspirational stories can mitigate the dangers without getting caught off guard by the critiques.

Chapter 5 - Exploring Representation

As Berger aptly demonstrates in *Ways of Seeing*, no matter how innocent the activity nor how trustworthy the actors, representing another human being necessarily redistributes the balance of power away from the represented to the representer. Whether painting a canvas, taking a photograph, recording a video etc. the creator of the representation has a significant amount of power over the subject, insomuch that he/she/they control how that person is depicted and presented to the world.

Sontag "sees the camera's popular incarnation as a predatory weapon which is 'loaded', 'aimed', and 'shot'. The camera is a 'sublimation of the gun' and 'to photograph people is to violate them (Sontag cited in Pinney 1992, 75). "By seeing them as they never see themselves, by having knowledge of them they can never have; [the camera] turns people into objects that can be symbolically possessed" (Sontag 1977, 14).

Now I'm not sure that I would go so far as to liken the camera to the gun, but with this violent metaphor Sontag emphasizes an important point: that representing someone else, or rather to "symbolically possess" them, puts them in a particularly vulnerable position. When a person becomes an object, that is a photograph, a painting, or video, they can be mistreated through the act of *re*presenting.

It is as if representation is a magical act, a here one moment gone the next illusion whereby the person, the complex, flesh and blood, feeling, breathing, dynamic person, is reduced to a simple image that is fixed, undeniable, easily confused for the truth and unproblematically stands for the whole. To emphasize the almost unperceivable gap between signifier and signified, between object and person (in this case animal) Christopher Pinney

repeatedly quotes the words of Allan Sekula "nothing could be more natural than... a man pulling a snapshot from his wallet and saying, "This is my dog' (1982, 86)" (Sekula cited in Pinney 1988, 77, 82 & 86). Of course that is not his dog, it is an object, a representation, a photograph of his dog.

Throughout history, and particularly in anthropology, the way researchers, travellers, conquerors, and people with power have documented and represented 'Others' has been highly problematic. For example, the way aboriginal people in Canada were represented in nineteenth century painting by French and English colonizers has been largely contested. Picturesque paintings by Lucious O'brien, Joseph Légaré and Paul Kane, for example, depict aboriginal peoples as 'Noble Savages', primitive, uncivilized barbarians, inextricably connected to the landscape and inevitably close to extinction (Ellingson 2001, Poulter 1994, Ryan 1990).

These representations have motivated at least two generations of aboriginal artists to respond with their own representation. Painting in the nineteen eighties and nineties first generation artists such as Carl Beam, Jane Ash Poitras, and Gerald McMaster have reclaimed artistic expression and have had certain success in subverting longstanding views of Canadian aboriginal identity (Ryan 1999). A second wave of artists working today: Kent Monkman, Terrance Houle, Brian Jungen and Aaron Paquette for example, are continuing to deconstruct hegemonic stereotypes, (re)vision history and present alternate images of Indianness.

Akin to the struggles of aboriginal people in Canada (not to mention a plethora of other marginalized groups worldwide), people with disabilities also struggle to advocate for their basic human rights, challenge misconceptions about their identity and secure control over how they are represented. My research with Project Citizenship has enabled me to expand my understanding of these complex issues.

When I first got involved in Project Citizenship, SKILLS was still figuring out how to best incorporate University of Alberta students. At one point it was decided that with help from SKILLS team leaders and other employees, the students would meet with an individual supported by SKILLS to film or take photographs, collect visual materials and create a story. Given scheduling constraints of student life and the brevity of an academic semester, most students would only meet the person once or twice before they would create the individual's story. A red flag immediately went up for me and I started thinking about representation, voice, authorship, and yes, power.

Learning of the authorship role granted to CSL students, I was overcome with the uneasy feeling that given the tools and power of representation the students (as able-bodied, affluent, researchers tied to an institution of power), could end up unintentionally misrepresenting people with disabilities and further marginalizing the very people the project aims to support. After speaking with leaders of Project Citizenship at SKILLS, filmmakers, and people with disabilities, I am discovering that that I had a pre-conceived conclusion as to how issues of representation ought to be properly addressed.

Using the experience of Canadian aboriginal artists as a tool to think with, I limited myself to believing that there could only be one solution for mitigating misrepresentation and that would be to allow the people with disabilities to tell their own stories, let them control the means of production, give them the power to express their own representations and public facing identities, and authorize them to determine the course of social change.

I am learning that the extent to which able bodied or non-disabled people are involved in the disability movement is a complex, deep-seated issue that extends beyond dynamics of representation. Scholars, advocates, people with disabilities and others have been wresting with the ideas of self-advocacy

and inclusion for some time. Following my initial line of thinking, there are those who strongly believe that people with disabilities should autonomously determine their own course of social action and advocate for themselves as much as possible. As Irving Zola has stated, "I do not claim that no one else can help or understand us; rather, I would argue that, as with women and blacks, we have reached that point in history, where having been there is essential in determining where to go" (Zola 1983, 57 cited in Shakespeare 1993, 254).

While it is easy to draw parallels between the disability movement and social struggles lead by other marginalized groups (aboriginal people, women, blacks and lesbians, gays, transgendered and bisexuals etc.), it is important not to skip over the differences. One notable difference is the extreme diversity in the expression and experience of disability among people who identify as being a part of this group. Now I'm not arguing that all women experience their femininity in precisely the same ways, nor do racial minorities suffer the same social condition. However, when it comes to disability, there is a broad range of experience.

Does having Multiple Sclerosis mean you have *been there* the same as a war veteran? Does someone who is hearing impaired have the right to speak for, advocate on behalf of, or determine the fate of another who cannot walk, eat or bathe without assistance? Wouldn't a parent, a caregiver, or a friend be better equipped to speak to an individual's needs and desires than a stranger who loosely identifies him or herself in similar disabled terms?

The trouble with Zola's perspective and others that lean towards a more autonomous self-advocacy movement is that they fail to recognize the inequitable social impacts that are introduced by a movement that does not address the totality of its members. As sociologist and disability rights advocate Tom Shakespeare points out,

"It is important not to ignore differences between impairments, despite the tendency of writers to gloss over difference in favour of the totalising and unifying role of oppression. Clearly, all disabled people face a common exclusion, prejudice and discrimination, and the vast majority share a condition of poverty. But beyond this, there are variations. Can I, as a person with restricted growth, effectively speak for or write about someone with cerebral palsy or visual impairment? I can identify with the basic social experience, but the details can be no clearer to me than they would be to anyone else, disabled or not" (Shakespeare 1993, 255).

The leaders I spoke with at SKILLS are keenly aware of this discussion and while they certainly recognize the need for self-determination and organization in some contexts, they profess to have had the greatest success with "collaborative" projects that embrace "partnerships" among people with disabilities and their able-bodied allies.

Ben from SKILLS explains,

> Ben: I think I've been sort of trained in the way that yes, there's varying levels of disability, right. There are some people that would say the self–advocacy movement is not great because it is segregating just people with disabilities working on social justice issues… if you're really into some political issue or some social justice issue where people are being wronged in some way, band together with anybody who's also interested in that, you know, people with disabilities or not.

It comes down to partnerships and negotiation. There are likely appropriate times and places for individuals to meet, share experiences, bond and come

together without involving able-bodied people. But excluding allies who are willing and able to offer support seems backward or even discriminatory within a movement that cites 'inclusion' as its fundamental goal.

Ben's colleague, Debbie, shares a similar perspective,

> Debbie: I have always felt really strongly about that, it's been my experience that… successful self-advocacy groups… have been people who are willing to partner up". But there is a caveat to this partnership, as Debbie says: "I mean, you gotta be good… because its so easy to just you know, take power. Good allies are people who know how to stand beside, stand underneath and support.

As Watson contends, "if you have come to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together" (1985). From the perspective of leaders at the SKILLS Society, allies of people with disabilities participating in the project (abled-bodied or not), ought to be able to gage their level of involvement, know when to assume responsibility and when to step aside. Making stories for Project Citizenship, then, calls for a level of self-reflexivity as it asks allies to be acutely aware of their position and asks them to know how to negotiate their role in flexible ways to better suit the needs of the individuals they are supporting. Raising the bar for the allies who support people with disabilities adds a degree of complexity and dynamism to the project and demands a certain quality standard from its partners.

This comes full circle to issues of representation. If able-bodied students in relative positions of power are representing people with disabilities and contributing to their betterment by taking pictures, making videos and telling stories, then they *gotta be good*. They have to be aware of their positions of

power and what is at stake when cameras and image making devices enter the frame.

Posted high on the gallery wall at the project's exhibit at the SNAP Gallery in September 2012, was a quote from disability rights pioneer Burton Blatt. It read, "Some stories enhance life and others degrade it. So we must be careful about the stories we tell" (Burton Blatt).

Figure 4

This quote is evidence that Project Citizenship is cognizant of the issues and risks surrounding representation. After speaking with filmmakers and people with disabilities who had their stories made, I am discovering that my fears concerning representation may have been more a product of my own academic background and inexperience in the field of disability than any real danger of representing people with disabilities in culturally insensitive ways. The project has done a *good* job of creating and telling stories in collaborative

ways and of negotiating power and control between people with disabilities and the people who support them.

More than putting this quote on the wall for the public to see, Project Citizenship implemented story making practices and techniques that focused on enhancing the lives of the people SKILLS supports. And they did so, not by giving representational control to people with disabilities, but by relying on the resources and talents of their able bodied allies (CSL students, filmmakers and storytellers) while teaching them, and trusting them, to use strategies for keeping their power in check.

One tactic the project employed was 'checking', that is checking-in with the individual represented in the story and including them throughout the story-making process. In the beginning, the people SKILLS supports were asked what they wanted their story to be about, what images they wanted to include and if there were making a short documentary, they were asked where they wanted to film. Further along in the process, the individual and their families were also considered throughout the editing and production phases.

According to Ben, during the editing phase of one story,

> Ben: the family was like, 'no I don't like how it's portrayed this way, it's not honest' and so we had to go back and say 'ok, so what would you like to make this more honest?' And then we went and changed it. But that was... tricky because we were like 'well we have deadlines, we got to get this ready for the show'... But we really had to hold strong and true to that idea that it's that the individual has to be at the helm, guiding it.

Filmmaker Steven Creswell expressed a similar practice of involving the individual throughout the story making process. Steven was hired by SKILLS for the summer months of 2012, and he was the main filmmaker/creator for approximately twelve out of twenty eight stories that went on display at the SNAP gallery.

> Steven: We would always bring the person with the disability in to my office and we would go through our own photos and they would pick which ones where their favorite or which one they felt told the tale that they were trying to tell best… Even though I was the one making the film, they would contribute. For example… in my mural story… Randy… was showing me pictures and the art that he'd done. And you know… this was his decision to share it with us and which pictures he would be sharing, it was all him. He had a lot of stuff he was proud of.

Although Steven was new to the SKILLS Society as well as working with people with disabilities, he discussed how it was important for him as a filmmaker and ally to represent the people he was documenting without taking too much control.

> Steven: So again, absolutely it's really important that we were doing these videos along side people with disabilities and not *to* them.

When I asked Ben and Steven if they thought the project had done a good job of ensuring that the people represented in the stories were involved throughout the story making process, they both agreed that they felt the project had done a decent job.

> I: So do you feel that you've done a pretty decent job of making sure that the people represented in these stories are included somehow?

Steven: Yeah I feel like we did a pretty good job of that.

However, when I spoke with people with disabilities about their involvement, it appears that their participation in the story making process was limited.

Wes chose his own music:

I: Did you pick this music?

Wes: Yeah, Jonny Cash (excited)

I: Yeah? Do you like Jonny Cash?

Wes: Oh yeah (smiling)

Danielle helped take photographs for her story:

I: And so what did you do for the project?

Danielle: Um. We took pictures I just talked about what I did and ah how it helps the facility and things like that.

I: Yeah. And did you take some of the pictures?

Danielle: Yes

I: And how did you choose which ones to take?

Danielle: Um. Well I mean I just kind of figured out what would work better, like... I kinda thought this would be good to show what I do and

how I do it and stuff.

Felix was involved in two stories. While he did not contribute to the making of the story about himself, aside from playing the leading role, he did participate in another story about citizenship by interviewing people at the Street Performers Festival about their definitions of citizenship.

> I: So I know back in September there was um a gala and an exhibit and there were about thirty stories on display
>
> Felix: Yeah, everybody else that did a story. A lot of people had stories. You know my Basketball story was there… and then the story about project citizenship was I was interviewing people… that was on there. I interviewed Nolan and I interviewed a very very very very tall guy.
>
> I: Super. Um did you help make [your] story at all?
>
> Felix: Um I didn't well I just made it up… Because the basketball thing you know it was great it was just what I just wanted to teach basketball and then my own story, they got kinda the story.

Looking back at my initial interview questions (Appendix B), I can see how my assumptions about mitigating representation permeated my research. The fact that I kept asking how people with disabilities were involved in the making of their stories shows how deeply I believed that representation or 'mis'representation could only be mitigated one way. It wasn't until I asked people with disabilities how they felt about their stories and if they would change anything that I began to question my perspective. Rather than 'mis'representation, as all representations reveal and obscure, the work with Project Citizenship has led me to a place of referring to negotiated representations that partially restore the representer/represented balance.

Wes:

Wes: They took a lot of pictures of me

I: Yeah? How did you feel about that?

Wes: I feel great! (Smiles). When I was talking to them I really, I was really proud of myself (laughs)…

I: Is there anything you would change or do differently in that story?

Wes: Nope. No, no

I: No?

Wes: I don't wanna change, I like I like what I'm doing, I don't wanna change that

I: Yeah

Wes: Yeah, I wanna keep it like it is, yeah

Felix:

I: You were at the gallery session in September?

Felix: I was at the gallery yeah

I: What did you think about it?

Felix: I thought it was awesome, it was great…

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I: And how did that make you feel?

Felix: It made me feel great, you know just to get out there and just talk to people and say you know 'this is my story, this is what I do'...

I: So is there anything you would change in your story?

Felix: Nnno (looking up and thinking about it), I think everything is great... everything is great, the basketball thing is going great and nothing, I don't think I would change anything.

Danielle:

Danielle: Yeah, it was a really neat experience

I: Yeah?

Danielle: Yeah, yeah it was very wonderful

Despite my leading questions and attempts to pull them in the direction of representation, the people with disabilities I spoke with did not express concern about how they were portrayed in their stories nor did they question their limited involvement in the story making process. Perhaps family members, film critics or vested academics could find stories or moments in them where people with disabilities are portrayed in ways that could be read as 'mis'representation. However, the feedback I got from people with disabilities about their stories was nothing short of joy, appreciation, and pride.

It could be that meeting me for the first time, they did not wish to disclose anything negative or criticize the project (let alone the people who support

them). However, listing to them and watching their faces light up when they talked about their stories and their experiences, I got the sense they were genuinely pleased about the project and their stories. I was humbled by their gratitude and slightly embarrassed by my assumptions. During these discussions I was beginning to understand how having a story to show and to share is of greater importance than worrying about the details of representation.

Further exploring strategies employed by the project, speaking with a more senior filmmaker revealed a technique for mitigating representation that does not necessarily require the subject to be involved in production. Lorraine self describes her filming process as "letting it be."

> Lorraine: Well most of the… types of film that I'm making are about what's unfolding and we make something out of what we get. I'm not shaping it too much… it's sort of *letting it be* and letting them be who they are, be important… just to kind of let it sit and be what it is. Without making a point that it's 'OK' that this is happening, *it just is*.

For this filmmaker, it is important not to overly control the flow of the story or emphasize a particular message or point of view. Within her filming process is a dedicated practice of letting things be what they are.

This "letting it be" style of filming resembles direct cinema, cinema verité, or what film critic and theorist Bill Nichols refers to as the observational mode of representation, which "stresses the nonintervention of the filmmaker" (1991, 38). While at times claiming to represent 'true' experience or the 'real' world, it is important to stress that observational style filming is not exempt from issues of representation. Frames are still shot from a particular point of view and later cut and edited to construct a story. Regardless of the filming style, the power of representation is still in the hands of the filmmaker.

However, "[observational] films cede "control" over the events that occur in front of the camera more than any other mode" (1991, 38).

In the context of portraying people with disabilities, the observational mode of representation, a filming style that relinquishes control, has particular benefits. Even though people with disabilities were not directly involved in the creation of their story, "observational cinema affords the viewer an opportunity to look in on and overhear something of the lived experience of others, to gain some sense of the distinct rhythms of everyday life" (Nichols 1991, 42).

> Lorraine: You know I mean I've made lots of film about people with developmental disabilities and I've always really I just wanna go in and be there. It's easy to judge on many levels how someone lives. Not just the fact that they're 'not smart' in certain aspects or whatever, but they way they live because they have a messy house or they have (laughs), you know, and I think when we let those things go and you just start to see a person, getting on with their life and living, then that's the key, it doesn't matter about the rest, the other stuff.

By portraying people with disabilities in an observational manner, audiences can see aspects of the daily lives of people with disabilities. Moreover, this style, which attempts to show people more or less as they are, helps to combat negative stereotypes and dominant narratives of disability.

> Lorriane: I think people have this sort of wrong notion that they're simple and nice and not complicated, that they are childlike, naïve and happy. Which is so wrong. They're as complex and different from each other as anyone else. So... it's a balancing act of trying to... not be overly sentimental, but... allowing a part of someone's personality that is simply enjoyable because they are like that. So it's not saying, "no, you

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can't, (laughing) you can't be happy", but it's watching how much that plays.

It is not that she chooses to avoid portraying people with disabilities as happy people enjoying their lives, but she chooses how much of that one-sided, sentimental, or dare I say 'inspirational' personality shines through. Even during the editing processes Lorraine continues in a "letting it be" style. In particular, when compiling footage into the final story, she selects clips that balance the tension between showing people as they are and being "overly sentimental."

> Lorraine: I'm not for cleaning things up too much you know, like let's make this look more acceptable… Even in the even in the editing…. something that I'm always very conscious of [is] being overly sentimental, I really want to stay away from sentimental with people with developmental disabilities.
>
> I: And why is that?
>
> Lorraine: It would be so easy to have sappy kind of music, you know, and be sentimental over the whole thing and I never want to go there, never wanna be that. But there are moments that present themselves that are humorous or funny that could be read that way, but in the balance we judge it's ok (laughs) it works, it's ok, we're not placating, were not downplaying anything you know. So it's that sort of thing. Not being too cute.

Adopting the observational mode of representation in filming citizenship stories achieves a number of things. Firstly, it recognizes the power of the filmmaker and attempts to shift representational control away from the filmmaker toward the events and players being recorded. Secondly, it allows

for different stories to be told. 'Letting it be', displays more complex and nuanced personalities of people with disabilities than are typically presented with other styles of filming. Thus, this mode challenges dominant narratives: the supercrip, human interest, or heroic stories of disability that reinforce negative stereotypes.

In some cases, asking people with disabilities to take control over the production of their stories may not be the desired course of action. Because people with disabilities have such a troubled history riddled with neglect, marginalization, and discrimination, many are not aware of the opportunities available to them for community engagement. Moreover, fewer still have been afforded the creative encouragement, intellectual space, nor financial means to conceive of and construct creative tales about their citizenship, let alone imagine how such stories could reach out to a public audience and incite social change. With more than twenty years of experience in the field, the leaders at the SKILLS Society stress the importance of being able to 'show possibilities'.

> Ben: We really wanna be honest to ask them, 'What do you need? What do you want? How can we support you?' all that kinda stuff, but... sometimes people really need to be shown possibilities. Especially people with disabilities that have just had services and they've been disappointed most of their life. For a lot of people when you ask them 'what would you like to be doing?' and 'imagine citizenship' they're just like 'What? No one's ever come to me like that'. So a lot of times you can't just go in and say 'oh were just gonna ask them what they want' and all they want to do is keep going bowling at the disability bowling alley you know... so a large part of it is to be able to show people.

> Debbie: Yeah (excited) like help people imagine better. We talk about that idea a lot, we need staff to imagine better. Like what would a better

life look like for Jack, you know, but also for people, for Jack to understand that you know, it's ok for him to imagine better. Like it's really way more than ok! Here's a menu of things to think about. I think [people] need to see other people with disabilities succeeding. Women have looked at other women, you know in the women's movement… you have gay people looking at Ellen and all those people [say] 'Hey', you know 'it's ok', you know 'I deserve that. They did that, why can't I?'.

Again I am learning that people with disabilities maintaining representational control over the creation of their stories is not as critical as I initially anticipated and their lack of autonomy may actually have benefits! By showing possibilities, these stories help build a repertoire of experiences and allow people with disabilities to construct their identities and sense of citizenship in previously unimaginable ways.

Moreover, the collaborative nature of these stories broadens the spectrum of imagined opportunities for everyone who comes into contact with them: creators who help construct them, subjects who appear in them and viewers who interact with and interpret them once they are constructed and shared. By not giving representational control to a single group, alternative narratives can be realized by all and new ways of living and being together in the world can potentially be fulfilled.

"Collaboration implies that meanings are negotiated, and/or conflicting meanings are performed to encourage audience members to find their own synthesis. In a sense all get their own voice by way of inclusion" (Norris 2009, 63). More than showing people with disabilities new opportunities, staff at SKIILS, allies, friends, family, and audience members in the greater community can imagine new, different and better possibilities for all citizens. This is what stories, and visual stories in particular can do. Images help us imagine.

Even though creators gave careful consideration to the construction of the stories and the people with disabilities are delighted with the result, one audience member indicated that he/she felt that the voice of people with disabilities was overshadowed by the storyteller's perspective.

In response to the question "What is your opinion of the visual and audio/visual medium of the stories?" he/she writes,

> A2: Most of the stories are told in third person, with strong visual representation supporting the 'narrator's' claims. While aware that first person storytelling is not always possible, I felt that the visual components were used to support the storyteller's observations.

This audience member expressed concern that the stories, or at least their visual aspects, represented the voice and opinions of a third party as opposed to the individual featured the film. Even though creators were careful to negotiate representation and the subjects of the stories where pleased with their portrayal, this audience member believed that the third person point of view influenced the representation.

Creators have limited control over how their creations are perceived once they start to circulate through the public domain. Regardless of the filmmaker's intention, a significant factor contributing to whether or not a story is judged to misrepresent, remains in the eye of the beholder. It is important not to lose sight of the power audience members, viewers and receivers have to interpret stories and the impacts these interpretations have when it comes to representing 'Others'.

The gala in September 2012 was my first opportunity to gather data and at that point the direction of my study was not fully identified. Therefore the

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survey questions for gallery attendees did not directly solicit feedback on what viewers thought about how people with disabilities were represented in the stories. In future studies, such direct questions would be worth including.

Additionally, I would have liked to have included the student story making experience in this study, beyond the video reviewed in chapter four. The two filmmakers I interviewed were fairly experienced and had an interest in the project that exceeded university credit. I know the CSL students did receive some training and advice from senior filmmakers and they met with project leaders before they began their work. However, it is not clear how much of the strategies and agenda supported by the project trickled down to the actual practices and behaviors of novice storytellers.

Likewise, it would have been beneficial to accompany students when they met people with disabilities, collected the footage and images they used, and to sit with them as they edited and constructed their final works. I can only judge by the stories themselves, the video titled "UofA Student Stories – Their Thoughts on Project Citizenship" and by speaking with the people with disabilities who appear in their videos to gain a sense of how CSL students may have employed the project's tactics or developed their own practices for mitigating issues of representation.

The notable benefits of including students in Project Citizenship are 1) that new allies were brought into the disability movement and 2) the finished citizenship stories where introduced into new arenas of society.

As Lorraine remarks,

> Lorraine: part of the success of [project citizenship] was… it threw a
> wide net, it had many participants so many stories got told… the

students would be able to tell their families… and when the final exhibition comes along there's a new audience who gets to witness the stories and perhaps you can meet the people so I think the best way forward is to always try to engage a little more out in terms of the community beyond the disability world."

Following the example of how aboriginal people were portrayed in artwork in the nineteenth century, I was fearful that if people with disabilities were not heavily involved in the creation of their representations, they could end up being portrayed in ways that undermine their dignity and reinforce inequitable power structures whereby the able-bodied are believed to be superior and thus are entitled to rights, privileges and a degree of citizenship not afforded to people with disabilities. However, the evidence suggests that even though their involvement in the production of their stories is limited, people with disabilities are carefully represented by others using methods that support or at least strive towards equitable power relations.

Of course they don't get it right all the time. With a project of this size, with such a large number of contributors, with such varied backgrounds, a certain level of variability among stories is to be expected. The leaders of Project Citizenship are the first to recognize that there is more work to be done. When we were talking about checking Ben said,

> Ben: yeah I, I think we've been pretty like, decent at it. I think its one of those things I don't think you can every say, 'yeah were perfect at it', that 'we're doing great with it'. Because I think as soon as you do that you might get into some sketchy territory where you're not really… checking it. So I think it's important to always have this sense that you know we can keep doing better, we have to make sure were not making assumptions.

This practice of self-reflexivity, checking assumptions and questioning bias is a key component to the ongoing success of Project Citizenship. As they continue to make stories and show possibilities to more people they support, leaders at SKILLS demonstrate commitment to continual growth and improvement of their story making strategies, which includes rethinking the involvement of students and other community allies and how best to include others in the process. This internal, critical reflection is vital for understanding and negotiating issues of representation and will only benefit future representations of people with disabilities.

Above all, what I am learning from this study is the importance of action in the face of reservation and forgiveness in the face of mistakes. What truly matters is that Project Citizenship's participants are willing to act in spite of the risks and are prepared to make mistakes and learn form them. The creation of citizenship stories (not to mention the considerable degree of introspection, care and compassion that is going into the story making process), is of highest importance. Mitigating issues of representation, while important, is a secondary consideration.

In hindsight, I feel my worries concerning representation may have been more a product of my own inexperience or lack of understanding than owing to any overt risk of misrepresentation. Project Citizenship is exceedingly self-reflexive, committed to recognizing bias and "not making assumptions." The filmmakers and project leaders have a keen understanding of the issues and are employing tactics to ensure people with disabilities are represented fairly. To some extent these strategies are being passed down to the students and other allies involved. This truly is a project of collaboration, connection and good leadership. There is still a long way to go, but what is apparent from this investigation into the stories made for Project Citizenship, is that change is not only possible, it is happening.

Through this research endeavor I have learned a considerable amount about stories, what they can do and what they can mean. Exploring audio-visual stories I am reminded both of the power of image and of the word heavy world in which we live. Despite exceptional advancements in visual technology, words and images remain profoundly intertwined. After a year of design, research, analysis and writing, I have reached a stronger understanding of my role as a researcher and as a storyteller. As I reflect on this experience and how far I have come, I hear a beckoning whisper, catch a fleeting reflection, that compels me to continue the collection of stories and hints at the long journey ahead.

I remember sitting in my grade two classroom just after I had moved from Nova Scotia. Skipping grade one I was younger and smaller than the other children, nervous and reluctant to make friends and eager to make a positive impression on the teacher. My father had recently given me a copy of *The Giving Tree* by Shel Silverstein, which I had brought to class for show and tell. In the interest of inclusion, my teacher asked me to share my book with a classmate with developmental disabilities named Robin (pseudonym). I can't remember if I was reluctant to share my book with him or not, but I do remember the hurt and confusion I felt when I looked over to find that Robin had spat all over the inside cover and rubbing it with his fingers, turned the page into a pulpy mess.

My grade two mind and heart missing the message of Silverstein's classic children's tale of unconditional giving, I now look back on that experience, my story, and draw a very different conclusions… an ongoing understanding and acceptance of people with disabilities through story.

Bibliography

Baggs, Amanda. 2007. Why we should listen to 'unusual' voices. *Anderson Cooper Blog 360°* [online], [cited Aug 11, 2013]. Available from: <http://www.cnn.com/CNN/Programs/anderson.cooper.360/blog/2007/02/why-we-should-listen-to-unusual-voices.html>

Barone, Tom, E. 1990. Using the Narrative Text as an Occasion for Conspiracy. *In Qualitative Inquiry in Education,* edited by E. W. Eisner & A. Peshkin. New York: Teachers College Press.

Barthes, Roland. 1977. *Image Music Text.* New York: The Noonday Press.

Barthes, Roland. 1981. *Camera Lucida.* New York: Hill and Wang.

Basso. Keith, H. 1996. *Wisdom Sits in Places: Landscape and Language Among the Western Apache*. Albuquerque: University of New Mexico Press.

Bauman, Richard. 1977. *Verbal Art as Performance.* Long Grove, IL: Waveland Press, Inc.

Berger, John. 1972. *Ways of Seeing*. New York: Penguin Books.

Bhabha, Homi K. 1994. *The Location of Culture.* New York: Routledge.

Blackledge, Adrian. 2000. *Literacy, Power and Social Justice.* Staffordshire, England: Trentham Books Limited.

Boas, Franz. 1911. *The Mind of Primitive Man*. New York: Macmillan Company.

Chatman, Seymour. 1981. What Novels Can Do That Films Can't (and vice versa). In *On Narrative,* edited by W.J.T. Mitchel. Chicago: University of Chicago Press.

Chion, Michel. 1994. *Audio-Vision: Sound on Screen.* New York: Columbia University Press.

Chrisman, Wendy L. 2011. A Reflection on Inspiration: A Recuperative Call for Emotion in Disability Studies. *Journal of Literary & Cultural Disability Studies* 5 (2):173-184.

Clare, Eli. 1999. *Exile and Pride: Disability, Queerness, and Liberation*. Cambridge, MA: South End Press.

Classen, Constance. 1993. Worlds of Sense. Chap. 6 in *Worlds of Sense: Exploring the Senses in History and Across Cultures.* New York: Routledge.

Connelly, E. M., & Clandinin, D. J. 1988. *Teachers as Curriculum Planners: Narratives of Experience.* Toronto: OISE Press.

Conners, R. D. 1978. Using Stimulated Recall in Naturalistic Settings – Some Technical Procedures*.* Technical Report 78-2-1 in *Occasional Paper Series.* Edmonton: Centre for Research in Teaching Faculty of Education University of Alberta.

Dalkir, Kimiz and Erica Wiseman. 2004. Organizational Storytelling and Knowledge Management: A Survey. *Storytelling, Self, Society.* 1(1): 57-73.

Darcy, Simon and Tracy Taylor. 2009. Disability Citizenship: an Australian Human Rights Analysis of the Cultural Industries. *Leisure Studies* 28 (4): 419-441

Denzin, Norman. 2001. *The Reflexive Interview and a Performative Social Science*. Qualitative Inquiry. 1(1):23-46.

Ellingson, Terry Jay. 2001. *The Myth of the Noble Savage*. Berkley: University of California Press.

Emerson, Robert, M., Rachel I. Fretz, and Linda L. Shaw. 2001. Participant Observation and Fieldnotes. Chap. 24 in *Handbook of Ethnography*, edited by Paul Atkinson et al. London: Sage.

Fiedler, Leslie A. 1982. Pity and Fear: Images of the Disabled in Literature and the Popular Arts. *Salmagundi.* 57(Summer): 57–69.

Frank, Arthur. 1996. *The Wounded Storyteller.* Chicago: The University of Chicago Press.

Geertz, Clifford. 1973. *The Interpretation of Cultures: Selected Essays.* New York: Basic Books.

Ginsburg, Faye. 2013. Disabilities in a Digital Age: Rethinking the Human Imaginary on and off Screen. *Frucht 2013. The Frucht Lectures* [online], [cited Aug 12, 2013]. Available from: https://sites.google.com/a/ualberta.ca/frucht-2013/

Graham, William A. 1987. *Beyond the Written Word: Oral Aspects of Scripture in the History of Religion.* New York: Press Syndicate of the University of Cambridge.

Haven, Kendall. 2007. *Story Proof: The Science Behind the Startling power of Story*. Westport, CT: Libraries Unlimited.

Herzfeld, Micheal. 1986. Closure as Cure: Tropes in the Exploration of Bodily and Social Disorder. *Current Anthropology*. 27(2):107-120.

Hoskins, Janet. 1998. *Biographical Objects: How Things Tell the Stories of People's Lives*. New York. Routledge.

Janesick, Valerie, J. 2001. Intuition and Creativity: A Pas de Deux for Qualitative Researchers. *Qualitative Inquiry.* 7(5):531-540.

Jay, Martin. 1998. Scopic Regimes of Modernity. In *The Visual Culture Reader*, edited by Nicholas Mirzoeff. New York: Routledge.

Jenks, Christopher. 1995. *Visual Culture*. New York. Routledge.

Kelly, John B. 2003. Inspiration. *Ragged Edge Online* [online], [cited Sept 17, 2013]. Available from: <http://www.raggededgemagazine.com/0103/0103ft1.html#bio>

Kendrick, Micheal, J. 2005. Some Possible Themes To Carry Us Forward. One Person at a Time Conference. *Kendrick Consulting International* [online], [cited Sept 15, 2013] Available from: <www.kendrickconsulting.org/PublicSite/Shared Documents/All publications/ThemestoCarryUsForward.doc>

Leavy, Patricia. 2009. *Method Meets Art.* New York: The Guilford Press.

Longmore, Paul K. 2003. *Why I Burned My Book and Other Essays on Disability*. Philadelphia: Temple University Press.

Lou, Hans C. et al. 2004. Parietal cortex and representation of the mental Self. *Proceedings of the National Academy of Sciences in the United States of America.* 101(17): 6827–6832.

Malinowski , Bronislaw. 1922. *Argonauts of the Western Pacific. An Account of Native Enterprise and Adventure in the Archipelagoes of Melanesian New Quinea.* London: Routledge & Kegan Paul Ltd.

Manning, Corinne. 2010. 'My memory's back!' Inclusive learning disability research using ethics, oral history and digital storytelling. *British Journal of Learning Disabilities*. 38 (3): 160-167

Martorella, Peter H. 1997. Technology and the Social Studies--or: Which Way to the Sleeping Giant? *Theory & Research in Social Education*. 25(4): 511-514

McColl, Mary Ann, Mike Schaub, Lauren Sampson and Kevin Hong. 2010. A Canadians with Disabilities Act? *Canadian Disability Policy Alliance*. [online], [cited March 30, 2013]. Available from: http://69.89.31.83/~disabio5/wp-content/uploads/2011/07/CDA-reformat.pdf

Mead. Margaret. 1928. *Coming of Age in Samoa: A Psychological Study of Primitive Youth for Western Civilisation*. New York: Quill.

Mehl-Madrona, Lewis. 2005. *Coyote Wisdom: The Power of Story in Healing*. Rochester, VT: Bear & Company.

Mitchel, David T., and Sharon L. Snyder. 2003. *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Ann Arbor: University of Michigan Press.

Mitchel, W. J. T. 1994. *Picture Theory: Essays on Verbal and Visual Representation.* Chicago: University of Chicago Press.

Nichols, Bill. 1991. *Representing Reality: Issues and Concepts in Documentary*. Bloomington: Indiana University Press.

Norris, Joe, McCammon, L., and Miller, C. 2000. *Learning to Teach Drama: A Case Narrative Approach*. Portsmouth: Heinemann.

Norris, Joe. 2009. *Playbuilding as Qualitative Research: A Participatory Arts-based Approach*. Walnut Creek, CA: Left Coast Press Inc.

O'Brien, John and Beth Mount. 1989. *Telling New Stories: The Search for Capacity Among People with Severe Handicaps*. [online], [cited July 30, 2013]. Available from: <http://www.eric.ed.gov/ERICWebPortal/search/detailmini.jsp?_nfpb=true&_&ERICExtSearch_SearchValue_0=ED345450&ERICExtSearch_SearchType_0=no&accno=ED345450>

Oliver, Mike. 1992. Changing the Social Relations of Research Production*? Disability, Handicap and Society*. 7(2):101-114.

Ong, Walter. 1988. *Orality and Literacy: The Technologizing of the World.* New York: Routledge.

Patton, Michael Quinn. 2002. *Qualitative Research and Evaluation Methods*. London: Sage.

Pink, Sarah. 2007. *Doing Visual Ethnography*. London: Sage.

Pinney, Christopher. 1992. The Parallel Histories of Anthropology and Photography. In *Anthropology and Photography*, edited by Elizabeth Edwards. New Haven: Yale University Press.

Polkinghorne, Donald E. 1988. *Narrative Knowing and the Human Sciences*. Albany: State University of New York Press.

Poulter. 1994. Representation as Colonial Rhetoric: The image of 'the Native' and 'the Habitant' in the Formation of Colonial Identities in Early Nineteenth Century Lowe Canada. *Journal of Canadian Art History.* 16(1):11-25.

Reason, Peter and Peter Hawkins. 1988. Storytelling as Inquiry. In *Human Inquiry in Action: Developments in New Paradigm Research*, edited by Peter Reason. London: Sage.

Richardson, Laurel. 1990. *Writing Strategies: Reaching Diverse Audiences. Qualitative Research Methods Volume 21*. London: Sage.

Riessman, Catherine, K. 2008. *Narrative methods for the human sciences*. London: Sage.

Roman, Leslie. G. 2009. The Unruly Salon: unfasten your seatbelts, take no prisoners, make no apologies! *International Journal of Qualitative Studies in Education* 22(1):1-16.

Rose, Gillian. 2007. *Visual Methodologies: An Introduction to the Interpretation of Visual Materials*. London: Sage.

Rose, F. D. 1996. Virtual Reality in Rehabilitation Following Traumatic Brain Injury. *International Conference on Disability, Virtual Reality and Associated Technologies* [online], [cited Sep 1, 2013]. Available from: <http://www.icdvrat.reading.ac.uk/1996/papers/1996_02.pdf>

Roulston, Kathryn. 2010. *Reflective Interviewing: A Guide to Theory and Practice.* London: Sage.

Ryan, Allan J. 1999. *The Trickster Shift: Humour and Irony in Contemporary Native Art.* Vancouver: UBC Press.

Ryan, Maureen. 1990. Picturing Canada's Native Landscape: Colonial Expansion, National Identity and Nineteenth Century Oceanic Voyage Literature. In *Double Vision: Art Histiries and Colonial Histories in the Pacific,* edited by Nicholas Thomas and Diane Losche. Cambridge: Cambridge University Press.

Saldaña, Johnny. 2009. *The Coding Manual for Qualitative Researchers*. Los Angeles: Sage.

Sarbin, Theodore, R. 1986. *Narrative Psychology : The Storied Nature of Human Conduct.* New York: Praeger.

Saukko, Paula. 2003. Combining Methodologies in Cultural Studies. Chap. 1 in *Doing Research in Cultural Studies*. London: Sage.

Sawyer, Richard, & Norris, Joe 2013. *Understanding Qualitative Research: Duoethnography*. New York: Oxford University Press.

Schweik, Suzan. 2011. Disability and the Normal Body of the (Native) Citizen. *Social Research*. 78(2):417-442.

Shakespeare, Tom. 1993. Disabled People's Self-organization: a new social movement? *Disability, Handicap and Society.* 8(3):249-264.

Shapiro, Esther. 1998. The Healing Power of Culture Stories: What Writers Can Teach Psychotherapists. *Cultural Diversity and Mental Health*. 4(2):91-101.

Sontag, Susan. *On Photography.* New York: Farrar, Straus and Giroux

Swatton, Susan and Jean O'Callaghan. 1999. The Experience of Healing Stories in the Life Narrative: A Grounded Theory. *Counselling Psychology Quarterly*, 12(4): 413-430.

Taylor, Daniel. 1996. *The Healing Power of Stories: Creating Yourself Through the Stories of Your Life.* Toronto: Doubleday.

Taylor, Sunny. 2004. The Right Not to Work: Power and Disability. *Monthly Review*, 55(10): [online], [cited May 8, 2013]. Available from: <http://monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability>

Tuckwell, Neil Brian. 1980. Stimulated Recall: Theoretical Perspectives and Practical and Technical Considerations. Technical Report 8-2-3 in *Occasional Paper Series*. Edmonton: Centre for Research in Teaching Faculty of Education University of Alberta.

Vonnegut, Kurt. 2006. *A Man Without A Country*. London: Bloomsberry.

Wade, Tracy K., and Juliette C. Troy. 2001. Mobile Phones as a New Memory Aid: A Preliminary Investigation Using Case Studies. *Brain Injury*. 15(4):305-320.

Waston, Lilla. 1985. Lilla Waston. *Wikipedia*. [online], [citied Oct 8, 2013]. Available from: <http://en.wikipedia.org/wiki/Lilla_Watson>

White, Hayden. 1981. The Value of Narrativity in the Representation of Reality. In *On Narrative,* edited by W.J.T. Mitchel. Chicago: University of Chicago Press.

Appendix A - Survey

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people represent and audience members.

Research Investigator: **Supervisor:**

Carmen Norris   Professor Marko Zivkovic
Department of Anthropology   Department of Anthropology
15-22 Tory Building, HM   13-28 Tory Building, HM
University of Alberta   University of Alberta
Edmonton, Alberta, T6G 2H4   Edmonton, Alberta, T6G 2H4
Email: carmen.norris@ualberta.ca   Email: marko.zivkovic@ualberta.ca
Phone: 780-710-8935   Phone: 780-492-5352

Dear audience member/gallery attendee:

In partial fulfillment of a Masters Degree in Anthropology, this research is designed to gather information on how people value and interpret the stories and images produced for Project Citizenship. You are being asked to be in this study because I am interested in your experience at this gallery exhibit, the interpretations you have on the stories you've seen as well as any impressions, opinions, or personal reflections you would like to share about Project Citizenship.

By investigating how people create, share and interpret stories and images we can gain rich insights into a society's cultural beliefs, collective ideas, and shared values. The goal of this research is to gain a deeper understanding of how Project Citizenship is using stories and images to both improve the lives of people with disabilities and challenge how society perceives disability.

There are 3 parts to this phase of the study: 1. Survey, 2. Gala Observations, and 3. Visual Methods

1.   Survey
If you are so willing, please provide your thoughts of the gala and the exhibit on the attached survey and place it in the ballot box labeled 'surveys'. If you are willing to participate in a follow-up interview, please fill in the last page of this invitation and return it to me or place it in the ballot box labeled 'interview'. You need not complete the survey to volunteer to be interviewed.

2.   Observations:
I am attending tonight's gala to witness audience reactions and better understand how the stories are displayed in relation to one another. The purpose is to better understand the project from different perspectives and in different contexts, which will support the information gathered during all research phases.

UNIVERSITY OF ALBERTA

FACULTY OF ARTS
DEPARTMENT OF ANTHROPOLOGY

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people represent and audience members

> 3.   Visual Methods:
> I will be taking digital photographs at tonight's gala and throughout the run of the exhibit. These images are being collected to record audience reactions and to get a sense of the types of people who attend the exhibit. As a public event, consent is not required to use these images for research. However, I will seek assent before taking photographs of specific individuals. Images will not be used of anyone who declines and no names will be collected.

You will benefit from this study by having the opportunity to reflect on the event in writing and share your opinions about the art gallery and the stories and images you have seen. It is my hope that the information gathered from this study will help us better understand how people value and interpret stories and images. For the SKILLS Society, the results of the survey may influence future projects and practices.

Participating in this study has risks. Given that the size of the project team is quite small, anonymity may not be guaranteed and those who read the final study may recognize your contributions. In such cases you may experience loss of privacy or damage to reputation. Your opinions may be criticized or opposed by those who read the study, which may lead to future tensions. That said, the readership for this thesis will be relatively small and it is unlikely for readers perspectives to affect you negatively in future encounters.

The survey data will be kept private. Only my supervisor and myself will have access to this information. Survey data will be copied into written form, kept secure on my personal computer and password protected. Everyone who volunteers for an interview will be given a code number and names will not be used. Identifying information will be kept on paper and kept in a locked cabinet in my office at the University of Alberta. Data will be kept secure for five years following the completion of this study, at which point paper data will be shredded and electronic files will be securely deleted.

The results of this study will be published as a thesis document and a paper copy will be housed at the University of Alberta. The publication will be available online with unrestricted distribution and it is possible that research findings may also be used in future journal articles and presentations. Participants will not be identified in any publications and data for all uses will be handled in compliance with the University of Alberta Standards. If you wish to receive a copy of my thesis once it is complete, please send me an email and I will happily share it with you.

To keep this survey anonymous, please separate the survey and place it in the ballot box labeled 'Surveys'.

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people represent and audience members.

You are under no obligation to participate in this study and submitting a survey is completely voluntary. Taking part in this study or not, will not affect your relationship with Project Citizenship or the SKILLS Society. Because your name will not be collected along with your survey, you will not be able to withdraw from the study after you have completed and submitted it.

If you have any further questions regarding this study, please do not hesitate to contact my supervisor Dr. Marko Zivkovic by email: marko.zivkovic@ualberta.ca or by phone: 780-492-5352 or myself by email: carmen.norris@ualberta.ca or by phone: 780-710-8953. If you have any questions or concerns about your rights as a participant, or how this study is being conducted, you may contact the Research Ethics Office at 780-492-2615. This office has no affiliation with the study investigators.

Thank you for your time.

Sincerely,

Carmen Norris, MA Student
Faculty of Arts, Department of Anthropology
University of Alberta
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

SURVEY

*In order to keep this survey anonymous, please place this page it in the ballot box labeled 'Surveys'. The Invitation to Participate is yours to keep and the Request for Interview form may be returned to the researcher or placed in the box labeled 'Interviews'. Thank you for participating in this study!

1.   Using between 10 and 25 words, what are your initial thoughts, feelings, and reactions to Project Citizenship's gallery exhibit?

2.   Are their any stories in particular that stand out for you? If so, how come?

3.   Has anything you saw or heard at the gallery influenced your perception of people with disabilities? If so, in what ways?

5.   What is your opinion of the visual and audio/visual medium of the stories?

6.   If this event were to be repeated, what recommendations would you make?

7.   Do you feel these citizenship stories will contribute to meaningful social change for people with disabilities? Why or why not?

8.   Is there anything else you would like to share?

REQUEST FOR INTERVIEW

Title of Project: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people represent and audience members

Investigator: Carmen Norris, MA Student
Faculty of Arts, Department of Anthropology, University of Alberta
Email: carmen.norris@ualberta.ca

To be completed by the participant

I am willing to be contacted to participate in a follow-up interview. I understand that I will be provided with a detailed interview invitation and can decline participation at any time without penalty.

_____   _____
Phone Number   E-mail Address

_____   _____
Signature of Research Participant   Date

_____
Printed Name

Appendix B – Interview Guides

Subject of the Story Interview Guide

Participant:

Date:
Time:
Location:
Interview Start Time:
Interview Finish Time:

1. What can you tell me about Project Citizenship?
   a. In your words, what is the project trying to do?

2. What has been your involvement in Project Citizenship?
   a. What have you been doing for the project?

3. Can you tell me a bit more about your story?
   a. What does your story mean to you?
   b. How has telling this story made you feel?

4. Have you been telling people about the project?
   a. If so, can you describe a time where you shared your story with someone?
   b. If not, how would you tell your story to someone you met for the first time?

5. Did you go to the gallery exhibit in September? If so, what did you think?
   a. Did you like sharing your story with all those people?
   b. Can you tell me about any of the other stories you saw?
   c. Do you have a special memory of the gala?

6. Did you help make your story? If so, can you describe what you did?
   a. For example were you asked to be in an interview? Did you pick the music?
   b. What were you thinking about at the time?

7. How do you feel about being in a film/painting/comic book?
   a. Would you like your story to be told in another way?

8. Do you feel your story shows the real you?
   a. Is there anything you would change or like to add to your story?

9. Is your life any different now that you have made and shared your story? If so, in what ways? If not, why not?

10. Do you feel sharing your story will help other people? Why or why not? If so, in what ways?

11. Is there anything else you would like to share about the project?

SKILLS Interview Guide

Participant:

Date:
Time:
Location:
Interview Start Time:
Interview Finish Time:

1. Can you tell me about Project Citizenship and its goals?
   a. Why has this project come about and what does it hope to achieve?

2. Can you tell me about your involvement in Project Citizenship?
      a. What have you been doing for the project?

3. Has your involvement in this project influenced or changed your perception of people with disabilities? If so, in what ways? Examples?

4. Has your involvement in this project impacted you in other ways? If so, in what ways? Examples?

5. As a leader at SKILLS, what do the citizenship stories mean to you?
   a. Has your interpretation of the stories changed over time?

6. Do feel these stories have had or will have an impact on the people who the stories are about? Why or why not?
   a. Do you feel these citizenship stories will contribute to meaningful social change for people with disabilities? Why or why not?

7. What do you hope people take away from these stories? (People at the gallery or people who watch them online). Was there a particular message you are hoping to convey?
   a. What did you intend the stories to mean?

8. Why stories? Why art?
   a. Why did you choose the medium(s) you did? (Film, painting, comic book etc.)

9. Do you feel that using visual materials holds a certain power over other methods when it comes to making and sharing citizenship stories? If so, in what ways? Examples?

10. How is Project Citizenship funded?

11. What role does funding play in the projects ability or decision to use art and story telling as methods for creating community connection and challenging perception of disability?

12. What have you learned from the project in the past year?
    a. Would you do anything differently next time?

13. What is next for Project Citizenship?

14. Is there anything else you would like to share about the project?

Participant:

Date:
Time:
Location:
Interview Start Time:
Interview Finish Time:

1. Can you tell me about Project Citizenship? What is your understanding of the project and its goals?
    a. Why has this project come about and what does it hope to achieve?

2. Can you tell me about your involvement in Project Citizenship?
    a. What have you done so far for the project?

3. Has your involvement in this project influenced your perception of people with disabilities? If so, in what ways? Examples?

4. Has your involvement in this project impacted you in other ways? If so, in what ways? Examples?

5. As a creator or co-creator of citizenship stories, what does the story mean to you?
    a. Has your interpretation of this story changed over time?

6. Do feel your story has had or will have an impact on the person who the story is about? Why or why not
    a. Do you feel your story will contribute to meaningful social change for people with disabilities? Why or why not?

7. What do you hope an audience member takes away from your story? Was there a particular message you were trying to convey?
    a. What did you intend the story to mean? Was there an agenda to your story?

8. What editorial choices did you make to present your message?
    a. What did you cut? Why did you include what you did?
    b. How do the techniques you use (cross fade, voice over, musical tracks, sound clips etc.) contribute to the message?

9. Why did you choose the medium you did? (film, painting, comic book etc.)
    a. Do you feel this form best represents the individual's story?

10. Do you feel that using visual materials holds a certain power over other methods when it comes to making and sharing citizenship stories? If so, in what ways? Examples?

11. Given that this is a story about someone else, what steps did you take to include the individual(s) in the production of his/her/their story?
    a. How was the individual involved in the story making process?
    b. How are his/her contributions recognized or given credit?

12. Would you do anything differently next time?

13. Is there anything else you would like to share about the project?

Appendix C – Consent Forms

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

Research Investigator:
Carmen Norris
Department of Anthropology
15-22 Tory Building, HM
University of Alberta
Edmonton, Alberta, T6G 2H4
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

Supervisor:
Professor Marko Zivkovic
Department of Anthropology
13-28 Tory Building, HM
University of Alberta
Edmonton, Alberta, T6G 2H4
Email: marko.zivkovic@ualberta.ca
Phone: 780-492-5352

Dear Project Citizenship storyteller:

You being asked to be part of a research study
- You are being asked to take part in this research study because I want to learn more about the stories and artwork made for Project Citizenship. I am asking you to be in the study because I want to hear more about how your story was made and what your story means to you.

What is a research study?
- A research study is a way to find out new information about something. You do not need to be in this research study if you don't want to.

If you join the study what will happen to you? If your join this study you will be asked to take part in an interview. I want to tell you about some things that will happen to you if you are in this study:
- I will ask you to sit with me and talk about Project Citizenship.
- I will ask you to answer some questions about your story and how you feel about Project Citizenship. It will take about 1/2 hour to do this.
- The interview will be audio recorded so I can refer back to it later.
- A family member, friend or support worker can be with you if you like.
- If your story is not publically shared, I need your permission before I can study it. I will ask you if it's ok with you if I take pictures of your story and use it in this study.

Will any part of the study hurt?
- The study will not hurt. If I ask you a question you don't like, you do not have to answer it. Only share information you want to.
- You can stop at anytime.
- If your name and your story were put on display to the public the SNAP art gallery or online, I would like to use your real name in this study. That way people will know it is you I am talking about.

UNIVERSITY OF ALBERTA

FACULTY OF ARTS
DEPARTMENT OF ANTHROPOLOGY

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

- However, there may be reasons you want to keep your name private. If you do not want me to use your name, I can keep it a secret.
- The Project Citizenship group is pretty small. Even if I keep your name a secret, there is a chance people might recognize what you have said. If that sounds too risky, you shouldn't take part in this study.

Will the study help you?
- The study may help you because you will be sharing your story with more people.
- This study also gives you the chance to share your feelings about your story and project citizenship.

Will the study help others?
- I may learn something that will help other people tell their own stories some day.
- Also, this study will help us learn more about how stories and art can make the world a better place.

Do your family or support worker know about this study?
- This study was explained to your family members and or support workers and they said that I could ask you if you want to be in it. You can talk this over with them before you decide.

Who will see the information collected about you?
- The information collected about you during this study will be kept safely locked up. Nobody will know it except the people doing the research.
- The study information about you will not be given to your family members or support workers. The researchers will not tell your friends or anyone else.

Do you have to be in the study?
- You do not have to be in the study. No one will be upset if you don't want to do this study. If you don't want to be in this study, you just have to tell me. It's up to you.
- You can also take more time to think about being in the study and talk some more with your family members or support workers about being in the study.

What if you have any questions?
- You can ask any questions that you may have about the study. If you have a question later that you didn't think of now, either you or your family member or support worker can call me or send me an email.

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

Other information about the study.
- If you decide to be in the study, please check off the boxes and write your name below.
- After the interview you can change your mind and stop being part of the study. All you have to do is tell me. It's okay. I won't be upset. I just ask that you please let me know by Feb 1, 2013.
- You will be given a copy of this paper to keep.

☐ Yes, I will be in this research study.　　☐ No, I don't want to do this.

☐ Yes, use my name in this study.　　☐ No, keep my name private.

* If you say 'Yes' your real name will be in the final report of this study and people who read it will know which parts are things that you have told me.

* If you say 'No', I will use a fake name for you in the final report of this study so people who read it will not know what parts are yours.

☐ Yes, you may take pictures of my story and use it in this study.　　☐ No, do not use my story.　　☐ Not Applicable (My story is public i.e. online)

_____　　_____　　_____
Participant's name　　Signature of the participant　　Date

_____　　_____　　_____
Person obtaining Assent　　Signature　　Date

Thank you for your time.

Sincerely,

Carmen Norris, MA Student
Faculty of Arts, Department of Anthropology
University of Alberta
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

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Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

Research Investigator: **Supervisor:**

Carmen Norris   Professor Marko Zivkovic
Department of Anthropology   Department of Anthropology
15-22 Tory Building, HM   13-28 Tory Building, HM
University of Alberta   University of Alberta
Edmonton, Alberta, T6G 2H4   Edmonton, Alberta, T6G 2H4
Email: carmen.norris@ualberta.ca   Email: marko.zivkovic@ualberta.ca
Phone: 780-710-8935   Phone: 780-492-5352

Dear Parent or Guardian:

In partial fulfillment of a Masters Degree in Anthropology, this research is designed to gather information on how people value and interpret the stories and images produced for Project Citizenship. By investigating how people create, share and interpret stories and images we can gain rich insights into a society's cultural beliefs, collective ideas, and shared values. The goal of this research is to gain a deeper understanding of how Project Citizenship is using stories and images to both improve the lives of people with disabilities and challenge how society perceives disability.

I am asking the person you support to be in this study because I would like to know more about his/her involvement in project citizenship, how he/she contributed to the making of his/her story, and generally what the story has come to means for him/her.

There are 2 parts to this study: 1. Interviews & 2. Visual Methods

1. **Interviews (about 30 minutes in length):**
I would like request one interview with the person you support, which may be held at a time and place that is most convenient for him/her. With his/her permission, the interview will be audio recorded and the information he/she shares with me will be kept confidential, unless he/she indicates that he/she would like his/her name to be acknowledged and credit granted to him/her for his/her contributions to the study.

There is always the chance that he/she may be asked to share personal information. He/she does not have to answer any questions that he/she does not feel comfortable answering. If he/she wishes to stop taking part in the study, please let me know verbally or in writing. His/her information can be removed from the study upon your request up until Feb 1, 2013. At that point detailed analysis and writing will have begun.

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

2. **Visual Material (photography, film, art etc.).**

The majority of citizenship stories are short films and are publically accessible online. However, some stories take on other forms (paintings, photographs etc.) and are not publically shared. In such cases, consent will be obtained before the stories are photographed and used in this study. The visual materials collected for this study will be analyzed along side the interviews as well as survey data collected during phase one of this study. Including visual materials is an important part of this research, as they will allow me to study the stories on their own as cultural objects as well as how they are created and interpreted by various participants and in different contexts.

The person you support will benefit from this study by having the opportunity to further discuss his/her story, explain what it means to him/her, describe his/her experiences of the story making process and share his/her opinions about Project Citizenship. It is my hope that the information gathered from this study will help us better understand how people value and interpret stories and images. For the SKILLS Society, the results of the study may influence future projects and practices.

Participating in this study has risks. Given that the size of the project team is quite small, anonymity may not be guaranteed and those who read the final study may recognize participants' contributions. In such cases the person you support may experience loss of privacy or damage to reputation. His/her opinions may be criticized or opposed by those who read the study, which may lead to future tensions. That said, the readership for this thesis will be relatively small and it is unlikely for readers perspectives to affect him/her negatively in future encounters.

All data will be kept private. Only my supervisor and myself will have access to this information. Audio files will be transcribed verbatim, kept secure on my computer and a back up medium and password protected. Everyone who volunteers for an interview will be given a code number and names will not be used. Identifying information will be kept on paper and kept in a locked cabinet in my office at the University of Alberta. Data will be kept secure for five years following the completion of this study, at which point paper data will be shredded and electronic files will be securely deleted.

The results of this study will be published as a thesis document and a paper copy will be housed at the University of Alberta. The publication will be available online with unrestricted distribution and it is possible that research findings may also be used in future journal articles and presentations. Participants will not be identified in any publications and data for all uses will be handled in compliance with the University of Alberta Standards. If you and/or the person you support wish to receive a copy of my thesis once it is complete, please send me an email and I will happily share it.

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

The person you support is under no obligation to participate in this study. Participating in an interview and/or allowing me to take pictures of his/her story are completely voluntary. Taking part in this study or not, will not affect his/her relationship with Project Citizenship or the SKILLS Society.

If you or the person you support has any further questions regarding this study, please do not hesitate to contact my supervisor Dr. Marko Zivkovic by email: marko.zivkovic@ualberta.ca or by phone: 780-492-5352 or myself by email: carmen.norris@ualberta.ca or by phone: 780-710-8953. If the person you support has any questions or concerns about his/her rights as a participant, or how this study is being conducted, you may contact the Research Ethics Office on their behalf at 780-492-2615. This office has no affiliation with the study investigators.

Thank you for your time.

Sincerely,

Carmen Norris, MA Student
Faculty of Arts, Department of Anthropology
University of Alberta
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

THIRD PARTY CONSENT FORM

Study Title: *Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.*

Research Investigator:

Supervisor:

Carmen Norris
Department of Anthropology
15-22 Tory Building, HM
University of Alberta
Edmonton, Alberta, T6G 2H4
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

Professor Marko Zivkovic
Department of Anthropology
13-28 Tory Building, HM
University of Alberta
Edmonton, Alberta, T6G 2H4
Email: marko.zivkovic@ualberta.ca
Phone: 780-492-5352

Note: should you provide consent on behalf of the person you support, the individual will also be asked to provide their permission (assent) before they participate in this study.

Do you and the person you support understand that he/she has been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet	Yes	No
Do you and the person you support understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you and the person you support had an opportunity to ask questions and discuss this study?	Yes	No
Do you and the person you support understand that you or he/she are free to refuse to participate, or to withdraw from the study, without consequence, and that his/her information will be withdrawn at your or his/her request?	Yes	No
Has the issue of confidentiality been explained to you and the person you support?	Yes	No
Do you and the person you support understand who will have access to his/her information?	Yes	No
As an authorized third party, I allow the person I support to take part in this study:	Yes	No

THIRD PARTY CONSENT FORM

Study Title: *Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.*

I accept that the person I support may be acknowledged and credit granted to him/her for his/her contributions in this study:

*By answering yes, the person's real name will appear in this study's final report, if he/she requests it.   Yes   No

*By answering no, the personal identity of the person you support will be kept confidential

I and/or the person I support grant permission for the researcher to photograph and use the participant's private citizenship story in this study:

                                                                                Yes   No

**If the story of the person you support is publically accessible (i.e. online) please leave this question unanswered.

This study was explained to me by: _____

I have read and understood the attached information letter and allow the person named below to take part in this study:

_____   _____
Name of Participant (please print)   Relationship to Participant (please print)

_____   _____
Name of Authorized Third Party   Signature of Authorized Third Party
(please print)

_____
Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to allow the person he/she supports to participate.

_____   _____
Signature of Investigator or Designee   Date

FACULTY OF ARTS
DEPARTMENT OF ANTHROPOLOGY

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

Research Investigator:

Carmen Norris
Department of Anthropology
15-22 Tory Building, HM
University of Alberta
Edmonton, Alberta, T6G 2H4
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

Supervisor:

Professor Marko Zivkovic
Department of Anthropology
13-28 Tory Building, HM
University of Alberta
Edmonton, Alberta, T6G 2H4
Email: marko.zivkovic@ualberta.ca
Phone: 780-492-5352

Dear SKILLS employee/Project Citizenship pioneer:

In partial fulfillment of a Masters Degree in Anthropology, this research is designed to gather information on how people value and interpret the stories and images produced for Project Citizenship. By investigating how people create, share and interpret stories and images we can gain rich insights into a society's cultural beliefs, collective ideas, and shared values. The goal of this research is to gain a deeper understanding of how Project Citizenship is using stories and images to both improve the lives of people with disabilities and challenge how society perceives disability.

You are being asked to be in this study because I would like to know more about what influenced the decision to use art and story telling as the methods for creating community connection and challenging perception of disability. I am also interested in learning what the citizenship stories mean to you, what you have learned from the story/image making process as and what is coming up next for project citizenship.

There are 2 parts to this phase of the study: 1. Interviews & 2. Visual Methods

1. **Interviews (about 30-45 minutes in length):**
I would like request one interview with you, which may be held at a time and place that is most convenient for you. With your permission, the interview will be audio recorded and the information you share with me will be kept confidential, unless you indicate that you would like your name to be acknowledged and credit granted to you for your contributions to the study.

There is always the chance that you may be asked to share personal information. You do not have to answer any questions that you are not okay with. If you wish to stop taking part in the study, please let the researcher know verbally or in writing. Your information can be removed from the study upon your request up until Feb 1, 2013. At that point detailed analysis and writing will have begun.

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members

   2. **Visual Material (photography, film, art etc.).**

The majority of citizenship stories are short films and are publically accessible online. However, some stories take on other forms (paintings, photographs etc.) and are not publically shared. In such cases, consent will be obtained from their owners (people with disability) before the stories are photographed and used in this study. The visual materials collected for this study will be analyzed along side the interviews as well as survey data collected during phase one of this study. Including visual materials is an important part of this research, as they will allow me to study the stories on their own as cultural objects as well as how they are created and interpreted by various participants and in different contexts.

You will benefit from this study by having the opportunity to further discuss the story/image making process, describe your interpretations of the stories that have been produced and share what you have learned from your involvement in Project Citizenship. It is my hope that the information gathered from this study will help us better understand how people value and interpret stories and images. For the SKILLS Society, the results of the study may influence future projects and practices.

Participating in this study has risks. Given that the size of the project team is quite small, anonymity may not be guaranteed and those who read the final study may recognize your contributions. In such cases you may experience loss of privacy or damage to reputation. Your opinions may be criticized or opposed by those who read the study, which may lead to future tensions. That said, the readership for this thesis will be relatively small and it is unlikely for readers perspectives to affect you negatively in future encounters.

All data will be kept private. Only my supervisor and myself will have access to this information. Audio files will be transcribed verbatim, kept secure on my computer and a back up medium and password protected. Everyone who volunteers for an interview will be given a code number and names will not be used. Identifying information will be kept on paper and kept in a locked cabinet in my office at the University of Alberta. Data will be kept secure for five years following the completion of this study, at which point paper data will be shredded and electronic files will be securely deleted.

The results of this study will be published as a thesis document and a paper copy will be housed at the University of Alberta. The publication will be available online with unrestricted distribution and it is possible that research findings may also be used in future journal articles and presentations. Participants will not be identified in any publications and data for all uses will be handled in compliance with the University of Alberta Standards. If you wish to receive a copy of my thesis once it is complete, please send me an email and I will happily share it with you.

Study Title: Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.

You are under no obligation to participate in this study. Participating in an interview and/or allowing me to take pictures of your story are completely voluntary. Taking part in this study or not, will not affect your relationship with Project Citizenship or the SKILLS Society.

If you have any further questions regarding this study, please do not hesitate to contact my supervisor Dr. Marko Zivkovic by email: marko.zivkovic@ualberta.ca or by phone: 780-492-5352 or myself by email: carmen.norris@ualberta.ca or by phone: 780-710-8953. If you have any questions or concerns about your rights as a participant, or how this study is being conducted, you may contact the Research Ethics Office at 780-492-2615. This office has no affiliation with the study investigators.

Thank you for your time.

Sincerely,

Carmen Norris, MA Student
Faculty of Arts, Department of Anthropology
University of Alberta
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

FACULTY OF ARTS
DEPARTMENT OF ANTHROPOLOGY

13-15 HM Tory Building
Edmonton, Alberta, Canada T6G 2H4
Tel: 780.492.3879
Fax: 780.492.5273

SKILLS EMPLOYEE CONSENT FORM

Study Title: *Interpreting Interpretations: Investigating how stories and images are understood by their creators, the people they represent and audience members.*

Research Investigator: **Supervisor:**

Carmen Norris   Professor Marko Zivkovic
Department of Anthropology   Department of Anthropology
15-22 Tory Building, HM   13-28 Tory Building, HM
University of Alberta   University of Alberta
Edmonton, Alberta, T6G 2H4   Edmonton, Alberta, T6G 2H4
Email: carmen.norris@ualberta.ca   Email: marko.zivkovic@ualberta.ca
Phone: 780-710-8935   Phone: 780-492-5352

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate, or to withdraw from the study, without consequence, and that your information will be withdrawn at your request?	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?	Yes	No
I agree to take part in this study:	Yes	No

I wish my name to be acknowledged and credit granted to me for my contributions in this study:

> *By answering yes, your real name will appear in this study's final report and people who read it will be able to identify your contributions.*

Yes   No

> *By answering no, your personal identity will be kept confidential.*

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This study was explained to me by: _____

I have read and understood the attached information letter and agree to take part in this study:

_____   _____

Signature of Research Participant   Date

_____

Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____   _____

Signature of Investigator or Designee   Date

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Dear Project Citizenship storyteller/creator/author:

In partial fulfillment of a Masters Degree in Anthropology, this research is designed to gather information on how people value and interpret the stories and images produced for Project Citizenship. By investigating how people create, share and interpret stories and images we can gain rich insights into a society's cultural beliefs, collective ideas, and shared values. The goal of this research is to gain a deeper understanding of how Project Citizenship is using stories and images to both improve the lives of people with disabilities and challenge how society perceives disability.

You are being asked to be in this study because I would like to know more about how citizenship stories were constructed, the creative decisions you made while creating them, as well as any personal reflections you have on the story making process.

There are 2 parts to this phase of the study: 1. Interviews & 2. Visual Methods

1. **Interviews (about 30-45 minutes in length):**
I would like request one interview with you, which may be held at a time and place that is most convenient for you. With your permission, the interview will be audio recorded and the information you share with me will be kept confidential, unless you indicate that you would like your name to be acknowledged and credit granted to you for your contributions to the study.

There is always the chance that you may be asked to share personal information. You do not have to answer any questions that you are not okay with. If you wish to stop taking part in the study, please let the researcher know verbally or in writing. Your information can be removed from the study upon your request up until Feb 1, 2013. At that point detailed analysis and writing will have begun.

2. **Visual Material (photography, film, art etc.).**
The majority of citizenship stories are short films and are publically accessible online. However, some stories take on other forms (paintings, photographs etc.) and are not publically shared. In

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such cases, consent will be obtained from their owners (people with disability) before the stories are photographed and used in this study. The visual materials collected for this study will be analyzed along side the interviews as well as survey data collected during phase one of this study. Including visual materials is an important part of this research, as they will allow me to study the stories on their own as cultural objects as well as how they are created and interpreted by various participants and in different contexts.

You will benefit from this study by having the opportunity to further discuss the story/stories you've made, explain what they mean to you, describe your experiences of the story making process and share your opinions about Project Citizenship. It is my hope that the information gathered from this study will help us better understand how people value and interpret stories and images. For the SKILLS Society, the results of the study may influence future projects and practices.

Participating in this study has risks. Given that the size of the project team is quite small, anonymity may not be guaranteed and those who read the final study may recognize your contributions. In such cases you may experience loss of privacy or damage to reputation. Your opinions may be criticized or opposed by those who read the study, which may lead to future tensions. That said, the readership for this thesis will be relatively small and it is unlikely for readers perspectives to affect you negatively in future encounters.

All data will be kept private. Only my supervisor and myself will have access to this information. Audio files will be transcribed verbatim, kept secure on my computer and a back up medium and password protected. Everyone who volunteers for an interview will be given a code number and names will not be used. Identifying information will be kept on paper and kept in a locked cabinet in my office at the University of Alberta. Data will be kept secure for five years following the completion of this study, at which point paper data will be shredded and electronic files will be securely deleted.

The results of this study will be published as a thesis document and a paper copy will be housed at the University of Alberta. The publication will be available online with unrestricted distribution and it is possible that research findings may also be used in future journal articles and presentations. Participants will not be identified in any publications and data for all uses will be handled in compliance with the University of Alberta Standards. If you wish to receive a copy of my thesis once it is complete, please send me an email and I will happily share it with you.

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You are under no obligation to participate in this study. Participating in an interview and/or allowing me to take pictures of your story are completely voluntary. Taking part in this study or not, will not affect your relationship with Project Citizenship or the SKILLS Society.

If you have any further questions regarding this study, please do not hesitate to contact my supervisor Dr. Marko Zivkovic by email: marko.zivkovic@ualberta.ca or by phone: 780-492-5352 or myself by email: carmen.norris@ualberta.ca or by phone: 780-710-8953. If you have any questions or concerns about your rights as a participant, or how this study is being conducted, you may contact the Research Ethics Office at 780-492-2615. This office has no affiliation with the study investigators.

Thank you for your time.

Sincerely,

Carmen Norris, MA Student
Faculty of Arts, Department of Anthropology
University of Alberta
Email: carmen.norris@ualberta.ca
Phone: 780-710-8935

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