

**LOOK, LISTEN, LEARN: COLLABORATIVE VIDEO STORYTELLING
BY/WITH PEOPLE WHO HAVE BEEN LABELLED
WITH AN INTELLECTUAL DISABILITY**

BY

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**A thesis submitted to the Faculty of Graduate Studies of the University of Manitoba
in partial fulfillment of the requirements for the degree of**

MASTER OF ARTS

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Abstract

In 2006, I began working collaboratively with People First members to use video as a means of telling experience-based stories. Although, I found little information that would help prepare me to work collaboratively with people who have been labeled with an intellectual disability. I was acquainted with participatory approaches to making video and with inclusive research methods with people with learning disabilities. After working for over two years and facing a variety of hurdles and barriers, *The Freedom Tour* documentary was released in DVD in 2008, and a year later, short video stories were published on the Internet as part of the *Label Free Zone* web-based project. After having worked intensely and with great urgency to “get these stories out,” I felt the need to pause. To reflect upon my experiences and to ask questions about the work I was doing, I chose to write stories adopting an auto-ethnographic approach. Experimenting with auto-ethnography as a method of inquiry and storytelling as a form of representation, gave me the opportunity to experience a process I had encouraged so many others to do: telling experience-based stories. I hope this study will increase our knowledge and understanding of collaborative video storytelling projects involving people who have been labelled. I also hope that by delving into and speaking from my experiences as filmmaker/facilitator, sibling and now auto-ethnographer I have contributed, if ever so slightly, to shifting our thinking about intellectual disability from a deficit perspective to an assumption of competence.

Acknowledgements

This study was possible thanks to the contributions of many People First members who generously acted as story consultants: Mark Blanchette, Kelly Cotter, Ruth Dopson, Melody Harlow, Bill Hogarth, Kevin Johnson, Richard Ruston, Tracy Ward, David Weremy, Susie Wieszmann and Valerie Wolbert. Thank you to People First of Canada for taking the leap into collaborative video making, I will be forever grateful for having had the chance to work with all of you on such an important project. I would also like to acknowledge the contribution of People First allies and *Freedom Tour* project collaborators who participated in this study: Christine Currie, Sara Harms, Erika MacPherson, Catherine Schaefer and Nicola Schaefer.

Thank you to my friend Fatia Wais for never letting me give up and for her valuable advice. Thank you to Nancy Hansen, my academic advisor in the Department of Disability Studies for her steadfast support throughout this long process and to my committee members Dr. Brenda Austin-Smith, Departments of English and Film Studies, and Dr. Jessica Senehi, Department of Peace and Conflict Studies, both at the University of Manitoba for their encouragement and support. A huge thanks as well to Sonia Barrette and Rachel Gouin for your support.

Thank you to my family and my kids who had to learn to live with me being cloistered away in my “home office” for long periods of time. Most of all, thank you to my mother who taught me not to accept things as they are and to my brother, Stéphane Boulanger, who taught me to resist assumptions.

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Prologue: A Scene From the Present

It is Spring 2012 and I am visiting People First members to wrap up my thesis work. I met this group of advocates labelled with an intellectual disability in 2005 during a protest. I had my video camera and they had something to say: shut down all institutions for people labelled with an intellectual disability. Since then, I have shared all kinds of experiences with them while co-creating *The Freedom Tour*,¹ a documentary film about institutions. I still keep in touch over the phone, email and Facebook. At the moment, I am back in Winnipeg where this all started. I walk up to Dave's building and punch in his number. Dave was the first institution survivor I had ever met. The line is busy. Mark, one of the People First self-advocates² who co-created the documentary, lives in this building too so I try his place. It rings. A familiar voice answers: “eeee-yellow?” “Mark, it's Josée” I yell into the panel. “Are you downstairs?” “Yes, I'm here at the door but Dave's line is busy, can you buzz me in?” He buzzes me in and meets me in the elevator. Mark gives a warm hug. His hair has grown and he's got a bit of a goatee. I notice he's wearing the yellow t-shirt.

I walk into Dave's apartment where he is on a conference call with the Joint National Task Force on Deinstitutionalization. Dave is a big burly man. His hands are huge, like farmers hands that have been tossing bales of hay for years. He talks loudly with his deep rich voice: his hearing is impaired. His hair is an unruly grey and his eyes are a clear blue. I have always worried when seeing him unsteadily walk up and down

¹ *The Freedom Tour*, 2008, DVD.

² According to People First of Canada, a self-advocate is someone who knows his or her rights and speaks for herself or himself. In this study, a self-advocate is also a person who has been labelled with an intellectual disability.

stairs and then marveled at how he could manage to sit on the ground, have a smoke and get himself up without any help at all. Dave has his phone on the speaker mode to listen in on the Task Force meeting. They are talking about the recent announcement by the Saskatchewan government to close down Valley View Centre,³ one of the institutions featured in *The Freedom Tour*. As I hear this news, a rush of emotions gives me the shivers: could Valley View finally be a thing of the past? Dave steps away from the speaker phone and gives me a warm bear hug. I hear someone on the conference call mentioning that there are plans to make more videos. I'm happy to hear that the video equipment bought by the National Film of Canada for People First chapters⁴ is still being used. I walk over to the living room and put my things down. I look on the wall and see an award Dave got back in 2008: "The Council of Canadians with Disabilities - National Award-2008" it says. Another plaque reads: "David Weremy Co-Creator (Director) of *The Freedom Tour* Manitoba League of Persons with Disabilities (MLPD). In recognition of his valued contribution to the Disability Rights Movement in Canada." Mark walks over to me and we start to chat. He tells me how some of the members cannot bear to watch *The Freedom Tour*, our documentary, over and over again, it makes them feel too sad and too angry knowing that MDC⁵ is still open. I agree with Mark, "It is a hard film to

³ The Joint Task Force on Deinstitutionalization defines an institution as "...any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day to day decisions. An institution is not defined merely by its size." <http://www.institutionwatch.ca>.

⁴ The NFB bought five mobile video production kits for People First chapters as part of their participation in the *Label Free Zone* web project.

⁵ MDC is the Manitoba Developmental Centre, a 'total institution' ("Total institutions" is a concept developed by Erving Goffman in his book *Asylums*, 1961 to understand how such a closed and regulated setting affects the people subjected to its rules and how they manage.) for people labelled with an intellectual disability. It is located in Portage La Prairie, Manitoba. MDC first opened as the Home for Incurables in the 1880s and was later renamed the Manitoba School for Retardates and the Manitoba School for Mental Defectives.

watch.”

Dave finishes his teleconference call with the Task Force and announces: “I’ve got a lot of work to do.” Dave has been relentless in his fight to close down institutions. “We should do another video Josée!” I agree, so much more needs to be said by people labelled with an intellectual disability. But in this thesis, I have chosen to speak from my own perspective to tell my story about myself and working with Dave, Mark, Susie, Valerie, Kevin and other people to make videos. I say, “Dave, remember, I’m writing a story about how we made *The Freedom Tour*? Your name will be in the story so people will know how we did the work. I’ll talk about some of our ups and downs. I’ll be writing from my own experience, what I’ve learned from making the film.” I have with me the final consent form for him to sign. “I just want to go over a few things to make sure it’s OK with you,” I tell him as I open up my laptop on his kitchen table. “Do what you have to do Josée” he says generously.

Introduction: Speaking From Experience

“So why are you interested in working with people with intellectual disabilities?” a mother asks me during a meeting with a local family coalition here in the Ottawa region. In her voice, I detect a mix of curiosity and incredulity. I have just introduced myself and my latest idea to start up a gardening project with people who have been labelled.. I tell her proudly: “My brother is labelled with an intellectual disability”. For me, it's personal: “C'est une histoire de famille.” Telling people about my family connection is my attempt to establish a connection and to say “I'm on your side.”

Before I begin talking about my experiences of making videos with people labelled with an intellectual disability, I have quite a few things to say about being a sibling. As a sister, I have always considered myself an insider. “To which communities do you belong?” one of my professors had asked us as communications students. I remember having a very difficult time answering that question when I was 23 years old. Fifteen years later, I can finally answer it: I am an ally of the disability community. I have long resisted the negative attitudes about intellectual disability. Now I simply resist the category “intellectual disability.” Sharing parts of my personal story in this study has been important in thinking about my role working in collaboration with people who have been labelled. It is also important because I have asked many people to share very personal moments of their lives without ever having to do so myself. Finally, it is also my way of demonstrating how disability can be “*defining* rather than *confining*”⁶ in the way that it has shaped who I am and who I continue to become, as Couser states:

Stimulated by the progress of the disability right movement, disability

⁶ Thomas Couser, “The empire of the “Normal”: A forum on disability and self-representation: Introduction,” *American Quarterly* 52, no. 2 (June 2000): 309.

autobiography is more likely in the future to take the form of autoethnography; that is, disability autobiography is more likely to explore the positive ways in which identity and life narrative are shaped by disability, the ways in which disability may *create* culture. (And, in a sense, self-representation by people with disabilities itself constitutes a form of disability culture.)⁷

I know, I am not a person labelled with a disability, I have only experienced it through my family. However, unless I die soon, my body and/or my mind will one day due to natural or other causes change in ways that will situate me as a person with a disability. It is only a matter of time, but as I write this, I am a sibling and an ally. In mainstream Canadian society (it is an understatement to say that), there is little room or time for people who do not measure up to ideals of efficiency, independence, beauty and intelligence. People who have been labelled with an intellectual disability are more likely to be thought of as a burden and as vulnerable persons who deserve pity rather than being perceived as fellow citizens. People often express admiration for the non-labelled people who support or work with them. How many times have I heard someone exclaim “Oh, you need lots of patience to work with them!” implying: “Good job! I could never do that!”

These attitudes have always bothered me since my brother is one of these labelled people. I see the work I have done since 2005 as a community filmmaker and this thesis as a result of my experience of disability as a sibling. My position as a French-speaking woman living in a dominantly English and patriarchal culture have shaped my ability to spot injustice. However, I have been frustrated by the racism⁸ present in minority

⁷ Ibid, 308.

⁸ As minority communities, francophones outside of Québec depend largely on immigration to develop culturally and to increase their numbers. In the past ten years, many French speaking immigrants have come from African countries and from the Caribbean. These new French speaking Canadians then become a racialized minority within a linguistic minority. Although Francophones have much to gain (especially politically) from this new influx of French speakers, racist mentalities about “les français de

francophone communities fighting for linguistic and cultural recognition and the elitism I encountered as a student in feminist collectives. Being the older sister to a brother labelled with an intellectual disability has situated me even further from the centre allowing me to connect with people who have experienced marginalization. I haven't experienced disability myself and have not experienced the consequences of labelling as my brother has. Because of the colour of my skin and the way I speak, no one has ever questioned my identity as a Canadian.

It was from these positions that I approached People First members to make personal videos: as a sibling, an ally and a privileged non-labelled person. I knew that People First members already used stories to share knowledge and to advocate for social change but that these stories were mostly available in print. Why limit these stories to print since so many self-advocates may not be able to read them? By drawing on my knowledge and experience with participatory video projects and the principles of inclusive research methods with people with learning disabilities, I embarked on a collaborative video storytelling project with People First members. My goal was to facilitate the process of making experience-based videos. Working with members of the People First self-advocacy movement just seemed to make sense: I felt at ease with people who have been labelled and this group already had experience with speaking up for their rights.

As I tried to find examples and descriptions of approaches to working alongside people who have been labelled to tell these stories, I found very little. Working in

souche” as in the “real francophones” or “real French-Canadian culture” create barriers that slow down and sometimes halt what could be mutually beneficial relationships...but that is another topic.

collaboration with people who have been labelled remained somewhat mysterious to me; therefore I hope that my stories will demystify the process. In this study I have adopted an auto-ethnographic approach to write about my experiences as a filmmaker experimenting with collaborative approaches to video storytelling.

In Chapter I, I will discuss some of the literature review I had done prior to beginning my work with People First self-advocates. I will also talk about some of my assumptions about people labelled with an intellectual disability and the label itself as well as provide a brief introduction to People First as a self-advocacy movement. I will build a case for using video to tell stories and will discuss the goals I had hoped to achieve through working collaboratively with people who have been labelled. My experience and understanding of disability pushed me to find methods that would help bridge the gap between labelled and non-labeled people. I wanted to help non-labeled people to understand so-called intellectual disability as a normal part of the human experience. I also hope to find a way to encourage non-labeled people to learn from the experiences stemming from this socially undervalued position. As opposed to text, video would allow self-advocates to speak for themselves and, with video's ability to reproduce reality, communicate directly with an audience. I believed that a collaborative method, just as much as the videos themselves, would contribute to breaking down many stereotypes about people labelled with an intellectual disability.

In Chapter II, I will discuss my preferences regarding the acquisition of knowledge and talk about the different approaches that may have been appropriate to conduct this study. I will explain why I have chosen to name my methodology auto-ethnographic and

provide some criteria for evaluating such an approach. The book that most inspired me to speak from personal experience was Alexandra Juhasz's *AidsTV*, especially the chapter she entitled WAVE: A Case Study⁹. It was her detailed account of working with women affected by AIDS that gave me the confidence to write about my experience.

In Chapter III, I will share stories about my personal experiences with disability as a sibling and proceed to the day when I began to work with People First self-advocates to collaboratively make a documentary. Many people could tell different stories about these experiences and from many different perspectives. I offer my own take on this experience as the filmmaker who facilitated the process and would like to learn from it. Although I have consulted with the five People First co-directors, PFC members as well as allies and other involved in the two year long process of making the documentary, I take full responsibility for the choices and interpretations given to the situations and events. I am speaking for myself as an outraged sister, committed filmmaker and researcher. In Chapter IV, I will reflect on what I have called an auto-ethnographic approach to writing. This will include the collaborative process of making the video, the questions of power that arose as a result, and of the potential for video storytelling to facilitate connections.

⁹ Alexandra Juhasz, *AIDS TV: Identity, Community, and Alternative Video* (Durham: Duke University Press, 1995): 179-228.

Chapter I: Background

This chapter will describe my understanding of intellectual disability and some of my assumptions about the power of storytelling through video to challenge dominant interpretations of this label. I will describe some of the social conditions I believe have perpetuated a pathological understanding of intellectual disability. I will briefly present the People First movement, and discuss the uses of video as a medium for telling experience-based stories by people who have been labelled. I will also outline my search for ways of working collaboratively.

You are Not Born Intellectually Disabled, It Is Something You Become.¹⁰

People who have been labelled with an intellectual disability¹¹ remain one of the most marginalized groups of people within society. The stigma associated with this identity is so powerful that it often overshadows individuality and even the person's humanity. "People who have been labelled with an intellectual disability are often denied other identities. The label of intellectual disability is all encompassing and so stigmatizing that the person's gender, religion, sexual orientation or cultural background is not even acknowledged as a component of their identity."¹² The combination of this stigmatizing

¹⁰ I adapted Simone de Beauvoir's expression and *On ne naît pas une femme, on le devient* which I had originally found as the title *On ne naît pas noir, on le devient: Les métamorphoses d'une idéologie raciste et esclavagiste* by Pierre Ndoumaï Harmattan, 2010.

¹¹ Throughout this study I use the terms "intellectual disability", "labeled with an intellectual disability" and "self-advocate" interchangeably to designate people who are considered to have a mental impairment based on a low IQ score, speech characteristics and facial features that fall outside the expected norm. According to the 2001 PALS survey, people labeled as having a developmental disabilities represent 3.5% of the Canadian population, learning disabilities 13.2%, speech 10.6%, memory 12.3%. The boundaries separating these categories are always shifting. <http://www.statcan.ca/Daily/English/021203/d021203a.htm>.

¹² Jan Walmsley and Kelley Johnson, *Inclusive Research Methods with People with Learning*

social identity and segregation has resulted in gross misrepresentations of people who have been labelled intellectually disabled in all areas of science and art. Out of sight and out of mind, people who have been labelled have had few opportunities to represent themselves to others. Dan Goodley explains how the label breaks dialogue and leaves people as objects of intervention.¹³ For decades, doctors, researchers, psychologists, social workers have had the authority to use words, images and narratives that objectify and dehumanize people labelled with an intellectual disability. The organization of society reflects this distance through parallel world in which labelled and non-labelled people inhabit. People who have been labelled have been objects and subjects of (pseudo) scientific and medical experiments, literary and visual works of art without any real benefit to them. All is lost not in these works because, at the very least, science and art leave traces of the ever changing attitudes towards and social position of people who have been labelled.¹⁴ Negative and false representation contributes to reinforcing stereotypes of helplessness, childishness innocence, danger, unpredictability, asexuality, burdensome, and most of all, incompetence.

Although I would rather not use the label “intellectual disability,” I have little choice since I have yet to find better language when referring to people who have been so-labelled. As I read bell hooks' reaction¹⁵ to this line by Adrienne Rich “This is the oppressor's language yet I need it to talk to you,” I felt it it conveyed the frustration of

Disabilities: Past, Present and Futures. London: Jessica Kingsley Publishers, 2003.

¹³ See Dan Goodley, “‘Learning Difficulties’, the Social Model of Disability and Impairment: challenging epistemologies,” *Disability & Society* 16, no. 2, 2001.

¹⁴ See for example Martin Halliwell's (2004) *Images of Idiocy: The Idiot Figure in Modern Fiction and Film*.

¹⁵ Bell hooks, *Teaching to Transgress: Education as the Practice of Freedom* (New York: Routledge, 1993), 167-168.

having to evoke the same categories that have oppressed people. Thankfully the People First movement has offered a temporary way out of this conceptual trap by adding “labelled with.” In this study, I alternate between using people labelled with an intellectual disability, self-advocates and labelled people.

As a result of the social model of disability, I have come to understand intellectual disability as a construct largely defined by a medical perspective that pathologizes difference. The value and the meaning we, as people, attribute to difference, is based on our cultural beliefs and interpretations and lived experiences. It is the process of interpretation, as explained in Blumer's theory of symbolic interactionism, that I hope stories have the potential to reach and to move:

The term "symbolic interaction" refers, of course, to the peculiar and distinctive character of interaction as it takes place between human beings. The peculiarity consists in the fact that human beings interpret or "define" each other's actions instead of merely reacting to each other's actions. Their "response" is not made directly to the actions of one another but instead is based on the meaning which they attach to such actions. Thus, human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the meaning of one another's actions.¹⁶

The interpretation in symbolic interaction is important because it is influenced not by the individual action itself, but by the expectations of certain categories of peoples' behaviour. It is difficult for us (regardless of our social position) to change our our interactions with others when assumptions are part of what philosopher Slavoj Zizek calls “the underground of the unspoken underpinnings of our everyday lives.”¹⁷ A person speaking

¹⁶ Herbert Blumer, “Society as symbolic interaction” in *Symbolic Interaction: An introduction in Social Psychology*, ed. Nancy Herman and Larry Reynolds (Dix Hills: General Hall, Inc., 1994), 263.

¹⁷ Slavoj Zizek, *Violence: Six Sideways Reflections* (New York: Picador, 2008), 168.

loudly in a public space is easily interpreted as threatening or as socially maladaptive behaviour (to borrow jargon from psychological testing) based on the “obscene underground”¹⁸ of assumptions about disability as deviant, lacking and tragic.¹⁹ Despite the difficulty to change this layer of interpretation, it is exactly what we must do. In their study on the social construction of humanness of people labelled with severe disabilities, Bogdan and Taylor explain that:

“Symbolic interactionism and labelling theory, though not by nature deterministic, often have been presented in terms of the inevitability of labelling, stereotyping, stigmatization, rejection, and exclusion of people defined as deviant, including those with recognizable disabilities.”²⁰

Despite this negative association, I have always seen the theory of symbolic-interactionism as a call to action. If, indeed we do learn from our environment and contribute to shaping it through interaction, then experience-based video stories with/by people who have been labelled have the potential to allow our most unconscious and unchecked beliefs to rise the surface, where they can be properly challenged. The deficit model of intellectual disability places the focus on peoples' individual behaviours and takes attention away from the social causes of marginalisation and the invisible or systemic violence that sustains it. Economic and social marginalization only exacerbate the differences and create situations of frustration that confirm assumptions: it is a vicious circle. Facilitating self-representation by people who have been labelled is key to deconstructing the notion of intellectual disability since “all representations have social

¹⁸ Ibid.

¹⁹ Dan Goodley, Griet Roets and Geert Van Hove, “Narrative in a nutshell: sharing hopes, fears, and dreams with self-advocates,” *Intellectual and Developmental Disabilities*, 45, no. 5 (2007): 325.

²⁰ Robert Bogdan and Taylor, “Relationships with severely disabled people: The social construction of humanness,” *Social Problems* 36, iss. 2, (1989): 135.

and political consequences.”²¹ It is about having the opportunity to affect the social meanings others ascribe to you in order to positively affect existing relationships and to increase the possibility of creating new ones.

My choice of video as the medium for sharing experience-based stories was primarily motivated by a desire to make this process more accessible to people who have been labelled. Through their personal videos, the inconsistencies between assumptions about people who have been labelled and their actual abilities as storytellers and advocates would be brought to the forefront. Although I did not expect commercial media to challenge assumptions and social categories through its programming, I did believe in the potential of community-based audiovisual media to affect change:

media production is based in both a complex cynicism and optimism about the power of the media. The mainstream will never change, *so we better do it ourselves*; our work will eventually contribute to real social change, that is why we do it. Activist video production must be simultaneously rooted in the belief that cultural capital is firmly entrenched and that it is infinitely dispersed.²²

Cultural capital can be seen as the knowledge that, as people, we have gained from our family and our access to formal education and other valued or devalued institutions. Having the label of intellectual disability attached to us as an individual closes most of the doors that could allow us to increase our cultural capital. Cultural capital is infinitely dispersed in the sense that socially marginalized people have valuable knowledge and ways of being that have the potential to, as Stone-Mediatore suggests,²³ contribute to a

²¹ Rosemarie Garland-Thomson et al., “The Politics of Staring: Visual Rhetorics of Disability in Popular Photography,” *Disability Studies: Enabling the Humanities* (2002): p. 75.

²² Alexandra Juhasz, *AIDS TV: Identity, Community, and Alternative Video*. Durham: Duke University Press, 1995. 80.

²³ See Shari Stone-Mediatore *Reading Across Borders: Storytelling and Knowledges of Resistance*. New York: Palgrave-MacMillan, 2003, 184.

better understanding of real-life events and to uncover the assumptions and the mindsets that resulted in the creation of concrete and oppressive institutions that benefit and welcome some people, while excluding others (I will return to Stone-Mediatore's ideas about storytelling and its epistemic value in Chapter IV: Lessons Learned.) Media activists' cynicism comes from the belief that mainstream commercial media will never acknowledge this and so they (and the people they work with), as differently situated people, must tell their own stories to redefine what constitutes valuable cultural capital. In other words, when people who have been labelled receive the support and have the power to tell their own stories using an accessible medium such as video, social stereotypes may be shattered since they do not fit the varied and complex realities of people with so-called intellectual disabilities.

For similar reasons, Inuit, Native and Métis struggled for over thirty years to gain control over their stories and images.²⁴ Until the advent of Inuit Broadcasting Corporation and later the Aboriginal People's Television Network (APTN), southern white producers formulated the stories and images broadcast to Inuit and Native communities. Stories, if they included Inuit or Native characters, portrayed them in very limited and stereotypical ways. Gary Farmer, a Native Canadian actor and producer, invited us to “[c]onsider the impression left on young Aboriginal people when they see themselves portrayed this way time and again. It's hard for them to have a positive image of themselves.”²⁵ The situation for people who have been labelled with an intellectual disability in 2012 is no better.

²⁴ Gail Guthrie Valaskakis, “Telling our own stories: the role, development and future of aboriginal communications,” (paper presented at the Colloquium for the Canadian Cultural Research Network/Réseau canadien de recherche culturelle, June 1998).
<http://www.arts.uwaterloo.ca/ccm/ccrn/documents/collg98valaskakis.htm>.

²⁵ “Images on screen promote aboriginal clichés,” *Ottawa Citizen Online*, Wednesday, February 12, 1997.

Consider this 2007 title in the *Globe and Mail* “Doomed from Birth to Death.”²⁶ You may be thinking “a person with Down Syndrome will not be reading this newspaper but how do you know? Even though standardized prenatal testing is having an impact on the numbers of people with Down Syndrome being born, these people are here among us right now and some read and write very well²⁷, and if they do not personally buy the *Globe and Mail*, a copy may still be available to them through their parents or staff.

Bérubé exposes the potential of experience-based stories by drawing on the history of the autobiographical genre as written by African Americans having escaped slavery:

The act of self-authorship performs the same performative function it did for Frederick Douglas and Harriet Jacobs and May Prince and William Wells Brown: it establishes the life writer as, at bare minimum, someone capable of self-reflection and self-representation, someone capable of life writing. And for populations considered constitutionally incapable of self-reflection and self-representation, that “bare minimum” is actually the crux of the matter, a meta-claim from which all other claims follow.²⁸

Although parents have been, and continue to be strong advocates for their labelled children, (including my own mother) their interests do not always coincide with their children's. For this reason, the act of telling one's own story and of speaking for oneself (by any format necessary) as a labelled person remains for me an important method for challenging society's most internalized

²⁶ Anne McIlroy, “Doomed from Birth to Death.” *Globe and Mail*, Saturday, May 5, 2007, Front page, Prairie Edition. This article tells the story of a woman with Down Syndrome who has developed Alzheimer’s disease. Could the message be any clearer? A life with Down Syndrome and any other so-called intellectual disability by association, is simply not worth living

²⁷ Roselyne Chevrette is one of these people, to read one of her poems, scroll down below the article on this page: http://www.inclusif.ca/?numero_journal=411.

²⁸ See Michael Bérubé, “Autobiography as Performative Utterance,” *American Quarterly* 52, no. 2 (June 2000): 341.

assumptions about people who have been labelled.

Social Conditions of People Living with the Label of Intellectual Disability

Since the arrival of the Canadian Charter of Rights and Freedoms in 1982, people with a so-called mental disability have had the same rights as every other Canadian citizen. Rights such as “freedom of opinion and expression” and “life, liberty and security of the person and the right not to be deprived thereof.” These rights exist yet people who have been labelled continue to live in large institutions²⁹ where some of them have lived their entire lives. People so-labelled continue to work in sheltered workshops for 5.00 or 15.00 dollars sometimes per week or per month, or for a few dollars per hour to recycle objects and to shred documents and stuff utensils into plastic packets. People I have spoken with did not know about minimum wage, some did not know their hourly wage since their money was managed by a provincially appointed guardian also known as a public trustee.

Post secondary education is still off limits because labelled people do not graduate with real high school diplomas. According to Community Living Ontario, 67% of students labelled with an intellectual disability are still not attending regular classrooms.³⁰ Students who are labelled as having a “mild intellectual disability” may be encouraged to obtain an Ontario secondary school certificate (OSSC) however, this is the equivalent of a

²⁹ Definition of an institution by the Joint National Task Force on Deinstitutionalization: “An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day to day decisions. An institution is not defined merely by its size.”

³⁰ Community Living Ontario. “Inclusive Education”, “Advocacy, Rights & the Law.” <http://www.communitylivingontario.ca/fr/node/1397>.

grade 10, which does not lead to college. Besides, according to Douglas College in British Columbia, “No disability related accommodations will mitigate for this disability in a post-secondary academic educational environment.”³¹ The door is effectively closed to people who fall into this category. Knowing how important post-secondary education is in mitigating the effects of poverty, statements like these hit me with their finality and blatant injustice. Has Douglas College ever spoken with people who have been labelled to discover or imagine the types of accommodations that people so-labelled may benefit from? The Campus Life³² program at the University of Manitoba is a step in the right direction to opening doors to higher education for labelled students.

In Ontario, students who have been labelled with “moderate” or “severe or profound” intellectual disability may receive a Certificate of Accomplishment (COA) that acknowledge the fact that they were in high school for five to seven years. As I tried to understand the types of diplomas available to students who have been labeled with some type of intellectual disability, I decided to call a local high school and speak with a resource teacher. Once she had explained the differences between an OSSC and a COA, I asked her “have you ever heard of one of your students then trying to attend college after obtaining their COA?” She responded with surprise: “Oh no! Well, that's never where they were going anyway. They might be going off to assisted living or to a day program.” According to the 2006 PALS survey,³³ only 32.7% of people with the label

³¹ Douglas College in British Columbia. “Cognitive Disability.” <http://www.douglas.bc.ca/services/centre-for-disabilities/documentation/cognitive.html>.

³² Education. “Breaking Barriers: Campus Life Student Exposes the Hurt of Being Excluded.” (March 29, 2012). <http://blogs.cc.umanitoba.ca/education/2012/03/29/breaking-barriers>.

³³ Statistics Canada. “Labour Force Participation and Unemployment rates by Disability Type, Canada, 2006.” *Participation and Activity Limitation Survey (PALS) 2006*. <http://www.statcan.gc.ca/pub/89-628-x/2008007/t/5201154-eng.htm>.

“developmental disability” were participating in the labour force. Since the link between educational achievement and employment is clearly understood for the rest of society, why does the label “intellectual disability” annul this relationship? I understand that our educational system, its teachers and even parents might *not expect* a labeled student to attend college or university but when asked, in the course of making video stories for the *Label Free Zone*, labelled peoples' aspirations were quite different from simply moving onto “assisted living.”

In fact, access to assisted living in the community is out of reach for most people who have been labelled with an intellectual disability. I would not consider living in a group home or an institution as assisted living. People who have been labelled, in most cases, do not choose where they live nor with whom they live. These decisions are often made by family members and services providers. This is no different for my own brother. Living on a fixed income and lacking access to sufficient funds to purchase support services that would allow them to get on with their lives, people are left with very few options. Common living arrangements are home share (based on a foster-care model), group homes, also called residences (owned and staffed by the same agency), nursing homes (and other long term residential facilities) and, staying at home with your family. My brother is still in this situation.

Publicly funded prenatal screening for Down Syndrome is now routine prenatal care for parents who are expecting. “In an international meta-analysis using data from the USA, UK, New Zealand, France, and Singapore, approximately 92% of women who receive a definitive prenatal diagnosis of DS [Down Syndrome] choose to terminate their

pregnancies.”³⁴ These statistics are not surprising in light of the social position of people who have been labelled with an intellectual disability. In this context, a rational parent



Fig. 1. “Go for it!” Dr. Brian Skotko – What He Learned from his Sister Who has Down Syndrome, http://www.youtube.com/watch?v=Jphpl_UnkL4

would prefer not to subject their child-to-be to these conditions. I know from the stories People First members have told and my own family's experience that doctors have been wrong about people's potential. For example, Heather would not live beyond

one year old, Seaward would never walk without crutches, David should not live in the community and Valerie was deemed legally incompetent. Stories based on personal experience correct prognoses based on a medical view of people labelled with an intellectual disability. These stories can also change the backdrop of individual pathology to one of social oppression. Although prenatal testing is described as providing greater control and choice to expectant mothers, it is difficult for me as well as many other disability activists and academics not to see it as a form of disguised eugenics³⁵. Although all of these statistics are useful and help me to convey the magnitude of the

³⁴ Mansfield C, Hopfer S, Marteau TM., “Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review. European Concerted Action: DADA (Decision-making After the Diagnosis of a fetal Abnormality).” *Prenatal Diagnosis* 19 (1999): 808–12. Cited by Brian G. Skotko in “With New Prenatal Testing, Will Babies With Down Syndrome Disappear?” *Archives of Disease in Childhood* 94, no 11 (November 2009).

³⁵ To highlight a fundamental bias in genetic counseling, Hansen, Janz and Sobsey state that ““If a genetic counsellor told a patient, “Your child will be female, which increases the risk of sexual abuse, domestic violence, and poverty,” we would not view that advice as neutral.” Nancy E. Hansen, Heidi L. Janz and Dick J. Sobsey, “21st Century Eugenics?” *The Lancet* 372, (December 2008): 106.

marginalization and devaluation of people who have been labelled, it is through experience-based stories as differently situated people, that labels such as congenital deformity, defect and chromosomal aberration begin to lose ground. Thus, the exclusion by social institutions begins to be perceived as injustice not as natural. Having lived with a sibling who has Down syndrome, Dr. Brian Skotko's story (who authored the article on prenatal testing I just referred to), shows how lived experience can supersede the medical training that often fails to address the human. I was not surprised to listen to him tell a funny story about his sister (see figure 1) who has an extra chromosome in the video “Go for it.”³⁶

In 2004, Canadians were asked how they thought other people would feel being around people with so-called developmental disabilities, 37% thought others would feel not very comfortable while 8% thought others would feel not at all comfortable. This is despite the fact that 75% of the people who had responded said they personally knew a person with a disability.³⁷ I wondered if they felt uncomfortable and so imagined that others would as well. How did they define “knowing someone” with a disability? Were they anticipating the discomfort of strangers in the presence of a person labelled with a developmental disability? I have seen support workers, family members try to protect others from feeling uncomfortable while in a public place with a person or many people who have been labelled. I have seen desperate attempts to try to control the behaviour of the person only to create situations that attract negative attention and confirm existing stereotypes that labelled people *are* like children and must be told how to behave. This

³⁶ To listen to this short story, go to: http://www.youtube.com/watch?v=Jphpl_UnkL4.

³⁷ Government of Canada, Office for Disability Issues, Social Development Canada. “Canadian Attitudes Towards Disability Issues: 2004 Benchmark Survey.” (April 2004).

discomfort that people feel or imagine in others that I have often seen place immense pressure on the non-labelled person, whether a family member, a support worker and, in some cases another labelled person,³⁸ to become the 'behaviour police'. I have felt this pressure myself in the company of people whose behaviour surpasses norms of what is acceptable. Why do I feel that people are looking to force this person to conform to social expectations of proper behaviour? As I discussed the continuing attempt to control labelled people's behaviour with a senior person working in the field of intellectual disability, he responded "You know, we have to congratulate ourselves for what we have achieved, a lot has been accomplished." I agreed that things had changed for the better but I think it is still quite early for congratulations.

People First: We Can Speak for Ourselves

Given the precarious social position of people who have been labelled, it is no surprise that "Label jars, not people" and "Nothing about us without us" are the two main slogans associated with the People First self-advocacy movement. In the early 1970s, people who have been labelled created their own organizations. As self-advocates, they have worked to defend their right to be treated as People First and not the medical label assigned to them by medical and social work professionals. At the very core of the People First self-advocacy movement is the principle of "speaking for ones self" instead of having another person speak for you. "People First challenges governments, service providers and communities to be aware of people who have developmental disabilities so

³⁸ Labelled people, like anybody else, are not immune to adopting controlling behaviours towards other people who are labelled and are behaving in ways that are considered socially unacceptable. Regardless of our labels, we have all been impacted by cultural expectations of acceptable behaviour.

we have to say what we want, it's not what other people want.”³⁹ Self-advocacy groups like People First are one of the few spaces where labelled people can express concerns, anger and opinions without the risk of being branded as non-compliant. In Canada, People First sometimes work in partnership with Community Living Associations to organize events such as conferences or to advocate for change as they have with the National Joint Task Force on Deinstitutionalization.⁴⁰ Community Living Associations were originally started by parents, whereas the People First movement was started by people living with the label. Community Living Associations have benefited from better funding, infrastructure and visibility than People First chapters. On the other hand, the People First movement in Canada benefits from its position as *the* national voice of people who have been labelled, hence the advantage of joining forces.

One of the important achievements for People First self-advocates has been their success in changing the name of what we know now as the Canadian Association for Community Living (CACL). Until the early 1980s, they were known as Association for the Mentally Retarded (AMR). “The name change was a great tool in that it brought everybody together from across Canada with the same thoughts...The terminology made you feel knee high to a grasshopper...” explains Peter Park (AKA the grandfather of People First in Canada.)⁴¹ Park explains that they faced a lot of resistance from AMRs who feared having their funding cut back. “We are asking for very little, and it’s time you stopped and listened! We are asking for the name of the Association (AMR) be changed

³⁹ Ruston, Richard. 2009. “People First of Canada” (video) Label Free Zone Youtube Channel. <http://www.youtube.com/watch?v=u4BYyqgqURY>.

⁴⁰ To learn more about the Task Force, visit: <http://www.institutionwatch.ca>.

⁴¹ Peter Park, Althea and Bruce Kappel. “People First. The History and the Dream,” *Making equality: history of advocacy and persons with disabilities in Canada*, ed. Deborah Stienstra, Aileen Wight-Felske and Colleen Watters (Concord: Captus Press, 2003), 370.

to a non-labelling name, whatever that name. We are proposing ‘Community Living.’”⁴² According to People First of Canada, the movement exists to “support people who have been labelled to speak for themselves and to help each other, and to help make sure that what people who have been labelled have to say is heard.”⁴³

Within People First chapters, support exists among members. Members support each other to accomplish a wide variety of tasks from counting money, taking notes, making telephone calls to providing emotional support to those experiencing difficult situations. However, each chapter must have an advisor before they can become an official People First group. The advisor is a volunteer whose role is to provide additional support to the members when needed. According to People First's booklet *Advice for Advisors*, they are organizers expected to provide information, help with decision-making, provide structure and assist with planning. The need for support in these areas varies according to each chapter's strengths and limitations. The advisor is meant to be a “facilitator and organizer of ideas, instead of the all-mighty expert.”⁴⁴ The author, Bill Worrell, goes on to explain that: “Learning starts from the concrete experience of one or several members; Learning is directly linked to concrete actions and results; Learning by doing, not by rote.”⁴⁵ The advisors I have met were most often non-labelled people who were support workers, community living employees, parents (as in the case of my mother) or siblings of people who have been labelled with an intellectual disability. Since so many groups are based on volunteerism, it can be difficult to retain advisors and turn

⁴² Ibid.

⁴³ People First of Canada. “About Us.” <http://www.peoplefirstofcanada.ca>.

⁴⁴ Bill Worrell, *People First: Advice for Advisors* (Downsview: National People First Project, 1988), 59-60.

⁴⁵ Ibid.

over is common. Many of these people are already in positions of authority in the lives of self-advocates and maintaining the role of facilitator can be complicated.⁴⁶ I will discuss the complicated nature of these relationships in Chapter III: Stories

Storytelling is nothing new for People First members and other self-advocates who have been labelled. Many disability organizations have used storytelling as a method of educating people about the experience of disability.⁴⁷ With the development of the disability arts movement⁴⁸ public celebrations of the experience of disability such as interdisciplinary arts and film festivals have created new platforms for stories in the form of film and video,⁴⁹ performance,⁵⁰ installations,⁵¹ dance, web art⁵² and visual arts. Within the context of Disability Studies programs such as Ryerson's, innovative online history projects like *Out From Under*⁵³ have been developed. I found many autobiographical stories written by or with people who have been labelled.⁵⁴ Sometimes they were called life stories or histories, autobiographies or personal stories. I also found many academics

⁴⁶ For a discussion about the role of advisors, see Dan Goodley, *Self-Advocacy in the Lives of People with Learning Difficulties*, Maidenhead: Open University Press, 2000), especially pages 17-21.

⁴⁷ For example the Canadian Down Syndrome Society (CDSS), Le Phénix: Au delà du handicap, People First of Canada, Canadian National Institute for the Blind and Community Living Associations.

⁴⁸ Read: "Camera...Lights...Attitude! Introducing Disability Arts and Culture," by Jihan Abbas, Kathryn Church, Catherine Frazee and Melanie Panitch.

⁴⁹ A few examples are the Sprout film festival: Making the Invisible Visible based in New York, Picture This...International Disability Film Festival based in Calgary, Kickstart Disability Arts and Culture based in Vancouver.

⁵⁰ For example the humorous song *Too many chromosomes to drive a car* by The Downbeats band.

⁵¹ Such as *From the Inside/OUT! Multimedia art and video project* with Woodlands School survivors and artist Persimmon Blackbridge in British Columbia.

⁵² See Ju Gosling's *Helping the Handicapped* at: <http://www.ju90.co.uk/help/eng/help1.htm>.

⁵³ Ryerson University's School of Disability Studies' "Out from Under: Disability, History and Things to Remember" describes itself as a "virtual museum of activist disability history." <http://ofu.ryerson.ca/about/index.html>.

⁵⁴ *Hear My Voice* by the Alberta Association for Community Living, 2006, *Life Landscapes: Saskatchewan advocate stories of success* by People First Saskatchewan et al. 2003, *Forgotten Lives: Exploring the History of Learning Disability* by Dorothy Atkinson et al. 2003, *Speakeasy* by Karin Melberg, Schwier, 1990, *A Celebration of Stories* by People First Ontario and People First of Canada 1993, only to name a few.

who used first-hand stories by people labelled with an intellectual disability as sources and in some cases co-wrote with labelled storytellers⁵⁵ in their research. These personal stories were told in very different contexts and for different reasons but they all valued the experience of people labelled with an intellectual disability.

Dan Goodley remarks that people who have been labelled with an intellectual disability are no longer just objects of scientific inquiry and are now recognized as the best authority on their own lives, experiences, feelings and views.⁵⁶ Although I learned much about people's experiences from these stories, I wanted to learn more about the *way* they had been produced. I tried to imagine the process to understand, the role of non-labelled researchers, editors, videographers and artists in the production of peoples' stories. I will now discuss the reasons that motivated me to use video as opposed to other media such as print or audio.

Using Video to Tell Stories Experience-Based Stories

I could see the role that video played in my brother's life. Since he never learned to read, DVDs, television, and now videos posted to the Internet, have always been his primary source of entertainment. Regardless if we have a label or not, here in North America the consumption of video is pervasive. With many Canadians having access to the Internet through mobile devices (like cellphones, ipads and ipods), computers and even television sets (the new so-called SmartTVs) we consume, produce and share video

⁵⁵ Researchers such as Erving Goffman, Robert Bogdan, Steven Taylor, Dorothy Atkinson, Jan Walmsley, Kelley Johnson, Dan Goodley, Rannveig Traustadóttir, again only to name a few.

⁵⁶ For example, Dan Goodley, 1996, Timothy Booth and Wendy Booth, 1994, *Dorothy Atkinson et al.*, 2003, Kelley Johnson and Rannveig Traustadóttir, 2000.

for (through YouTube.com and Facebook.com), and we also communicate with others thanks to video (for example Skype and Facetime).

I asked Valerie, one of the co-directors of *The Freedom Tour*, what she thought about our choice of video to tell stories of surviving institutions: “Video is good for telling people's stories and getting the message out... It's very educational. A video is more expressive, you can tell expressions, moods. In a book, some people wouldn't be able to read it and we tried to make our video plain language. Sometimes books aren't plain language. We could actually show our feelings.”⁵⁷ The advantage of video to show emotions was important considering that people labelled as retarded were believed to have very little or no feelings at all. Although a person may not use words or her own voice⁵⁸ to communicate, the audience could nonetheless connect to her and to her story as it is told by a family member or a trusted friend. Although the audience does not hear her directly telling her own story, video allows to see her in her home and interacting with others. In this situation, perhaps video acted as a witness saying “See? This is a real person with feelings, like you.” I hoped that video could induce the sort of “seeing is believing”⁵⁹ effect.

“Thompson (1988, p. 230) notes that the translation of speech into prose instantly mutilates the story being recanted.”⁶⁰ Of course, a story can be told by including original

⁵⁷ Josée Boulanger, Susie Wieszmann and Valerie Wolbert, “*The Freedom Tour* documentary: An experiment in inclusive filmmaking” in *Living the Edges: A Disabled Women's Reader*, ed. Diane Driedger, (Toronto, Inanna Publications & Education, 2010), 350.

⁵⁸ Some people may use alternative communication devices. Some of these generate speech, others make use of images, text and video. Applications are designed for iPods and iPads.

⁵⁹ Inspired by similar ideas found in the documentary *Seeing is Believing*: <<http://www.seeingisbelieving.ca>> and the Witness.org <<http://www.witness.org>>

⁶⁰ Dan Goodley, “Tales of hidden lives: a critical examination of life history research with people who have learning difficulties,” *Disability and Society* 11, no. 3 (1996): 339.

dialogue but that would, as Valerie noted, exclude people who don't read. When using video, the audience could see and hear the person telling their story. The storyteller's words could not be changed. Some words could be edited out and sentences rearranged but different words could not be put into the person's mouth. Although the storyteller might hesitate and make mistakes during an interview or a scene, the editor could, with their permission, "clean it up" for the purpose of clarity. Repetitions and verbal expressions that take away from the story could be taken out. How would this type of editing be any different from the mutilation⁶¹ Thompspon speaks of?⁶² I will get some help from Bourdieu to discuss the ethics of editing in the section on *Post-production or video editing* in Chapter III: Stories.

Labelled or not, we have a lot of experience with video. So much so that its language and conventions have become "naturalised and accepted (...) as a 'realistic' mode of representation."⁶³ By using video to tell stories, the audience could see the person in action, they could hear her talking. This realist quality of video created an illusion of "being there" with the person. I hoped that this effect might create a moment of intimacy between storytellers and audience. I may have entertained fantasies of the ability to film people in the Direct Cinema style where it was believed that a "good film crew" could capture reality as it really happened and without interference but those fantasies did not last long. A *cinéma vérité* approach as "overtly interventionist; interrupting film subjects,

⁶¹ It is interesting to mention that synonyms of the verb to mutilate are to "cripple, disable, incapacitate, lame, maim". Two definitions of mutilate illustrate the correspondence of disability with pathology embedded in language: "1: to cut up or alter radically so as to make imperfect <the child *mutilated* the book with his scissors>, 2: to cut off or permanently destroy a limb or essential part of: cripple." Source: <<http://www.merriam-webster.com/dictionary/mutilate>>

⁶² Thanks to Brenda Austin-Smith for asking.

⁶³ Anita Biressi and Heather Nunn, *Reality TV: Realism and Revelation*, (London: Wallflower Press, 2005), 39.

interacting with them and even filming their responses to rough-cuts of film footage by the filmmaker”⁶⁴ seemed more appropriate and transparent about the impact of a film crew on events and storytelling. I had appreciated self-advocates' ability to “tell it like it is.” I saw their stories as direct, honest and I loved the “in your face” quality of some of these stories. Video could literally lift these stories off the page and bring them to life with movement, colours, sounds and music.

Video also had the advantage of being open to different forms of translation; one DVD, a video could be dubbed into different languages including sign language. A video could contain open or closed captions as well as video description. It also allowed for the use of illustrations and pictures to add images to peoples' words, to make easier to understand and to remember. As I thought about video my medium of choice for working with people who have been labelled, I could not help but wonder how many storytellers could read their own stories or others' stories published in books. “For whom were these stories published?” I asked myself. From this perspective, video again appeared as the best medium: regardless of storytellers' literacy skills, they could view their own stories and ones by other self-advocates. My brother is a good example: he regularly views his own video story as well as the other the French-language⁶⁵ videos made as part of the *Label Free Zone* project. Following this logic, people who have been labelled could also access the opinions and testimonies of non-labelled allies or parents who were “on their side”. It represented a small step toward including this group of people in a much needed

⁶⁴ Ibid, 40.

⁶⁵ To watch his video, go to: <http://www.youtube.com/playlist?list=PLzYPfmRgiX7197uoScsGJJ2YuwlWM48I>. Stéphane's story has the most hits since he loves to watch it over and over again. I have bookmarked it in a large icon to make it easier for him to find it whenever he spends time on Youtube.com.

dialogue about things that matter to them. Above these considerations of accessibility, video requires a group effort. It is rarely something people do alone. Unlike writing which is more solitary, video production is a group activity. As video cameras continue to become lighter, cheaper and easier to use, it becomes easier to use them for this purpose. Regardless of my excitement about the possibilities of video, questions remained: Would the knowledge produced using these approaches and through this medium be recognized as valuable? If so, by whom?

Looking for an Approach to Working with People Who Have Been Labelled

Whether in research or in filmmaking, approaches aiming to democratize or render more accessible are often seen with suspicion by those who profit from elitist conceptions of theory and art. The credibility of the researchers and filmmakers rests on mastering a certain language, conventions and adopting approaches considered legitimate. When researchers and filmmakers question these conventions they are sometimes accused of not being real researchers or not creating real theory.⁶⁶ Autobiographical approaches hold much potential for destabilizing notions about theory, research and the category “intellectual disability”. However, these approaches struggle against the stigma of being perceived as popular literature for the less well educated. The inclusion of people who have been labelled, along with many other people who do not master abstract academic language, depends on approaches that make research and theory accessible both in terms of production and reception. For example, People First self-advocates often ask for Plain

⁶⁶ bell hooks, *Teaching to Transgress: Education as the Practice of Freedom* (New York: Routledge, 1994), 63-64.

Language⁶⁷ versions of meeting agendas, supporting material and laws that directly affect them. When information is not presented in accessible language, people are left out along with their potential contributions. Regarding the inclusion of people labelled with an intellectual disability and awarding them research contracts, UK self-advocate Simone Aspis asks: “what is everyone afraid of: their profession being deskilled and devalued, which may have an impact on the high status that social research has had?”⁶⁸ Imagine if a large proportion of this group of people could access and understand the research that has been done (and continues to be done) about them in the last one hundred years. Much like people with physical disabilities, women, Native, LGBLT and racialized people, they would have a lot to say. This is the reason why it is important to discuss approaches that have the potential to include people who have been labelled in knowledge production processes.

This fear of “dumbing down” the art of filmmaking was expressed as the new technology of 8mm film became available and the idea of “putting media in the hands of the people” gained popularity at the National Film Board of Canada. John Grierson, the Board's first Commissioner, expressed this attitude towards widening the access of media production to more people when he said “It troubles me to see people loosely waving a camera around... I shudder at all catch-as-catch-can film approaches, even when they claim to be catching a falling star” and in addition: “I am all for the 8mm revolution, so

⁶⁷ Plain Language, according to the Center for Plain Language, is “Focused on readers”, they ask: “Can the people who are the audience for the material quickly and easily find what they need, understand what they find and act appropriately on that understanding?” Source: <http://centerforplainlanguage.org/about-plain-language>.

⁶⁸ Simone Aspis, “Researching our history: who is in charge?” in *Crossing Boundaries: Change and Continuity in the History of Learning Disabilities*, ed. Lindsay Brigham et al. (Kidderminster: BILD Publications, 2000), 2.

long as the 8mm mind doesn't go with it.”⁶⁹ In his PhD dissertation, David Barker Jones remarks that “film-makers - it could be argued, were 'copping out'.”⁷⁰ This 'copping out' or “near abdication” explains Wiesner, was for Jones a result of “the filmmakers' reluctance to set the agenda, to impose their view as a gatekeepers in the selection and treatment of topic for the documentary.”⁷¹ However, when Simone Aspis says “It's never us [people who have been labelled with a learning disability] who get the research contracts so we are never in charge of setting the agenda,”⁷² it seems to me that there is a need for filmmakers and researchers willing to abdicate their authority if people who have been labelled are ever going to set the agenda or the point of vu. I have also encountered an attitude of resistance when discussing accessibility for people who have been labelled with an intellectual disability. Reactions would sound like “It's impossible to make everybody happy” or “A website will never be accessible to everyone.” Perhaps I had presented my ideas in a way that made people feel defensive. Was I a ridiculous idealist about accessibility? I did not understand this resistance because I saw the goal of accessibility for all as a creative challenge.

People who have been labelled with an intellectual disability depend, as Walmsley

⁶⁹ John Grierson, “Memo to Michelle about decentralizing the Means of Production (1972),” in *Challenge for Change: Activist Documentary at the National Film Board of Canada*, ed. Thomas Waugh et al. (Montreal & Kingston: McGill-Queen's University Press, 2010), 62.

⁷⁰ Peter K. Wiesner, “Media for the People: The Canadian Experiments with Film and Video in Community Development (1992),” citing David Barker Jones, *The National Film Board of Canada; the development of its documentary achievement*, Stanford University Ph.D. Dissertation. Ann Arbor, Michigan: University Microfilms, 1977 in *Challenge for Change: Activist Documentary at the National Film Board of Canada*, ed. Thomas Waugh et al. (Montreal & Kingston: McGill-Queen's University Press, 2010), 80.

⁷¹ Ibid.

⁷² Simone Aspis, “Researching our history: who is in charge?” in *Crossing Boundaries: Change and Continuity in the History of Learning Disabilities*, ed. Lindsay Brigham et al. (Kidderminster: BILD Publications, 2000), 2.

puts it “on a team approach”⁷³ to accomplish such things as telling experience-based stories using video. This is obviously not without its problems since “collaborative life writing all raise serious questions as to voice, agency, authority - the politics of representation.”⁷⁴ This is one of the reasons that motivated me to describe and discuss the nature of the collaborative approaches adopted to make videos with People First members. Adopting a collaborative approach to life stories or, video storytelling in this case, was based on an assumption of competence rather than incompetence.⁷⁵ However, simply naming the approach as collaborative means very little since like the participatory approach, it can cover a wide range of practices. I wanted to clarify what collaboration looked like in the particular context of making *The Freedom Tour* documentary film and draw from experiences of making personal videos for the *Label Free Zone* website, because so little has been written about what happens during collaborative video or multimedia projects with people who have been labelled with an intellectual disability. I could find no examples that satisfied my desire to learn about collaborative approaches in working with this group of people.

In the field of education, narrative approaches such as case methods and self-study invite teachers to learn from their own experience to improve their practice. But, for those of us working on projects with non-profit organizations or community-based associations, the knowledge and insights gained are often lost in the wind once the project is completed. For this reason, I decided to outline how I worked with People First members

⁷³ Jan Walsmley, “Normalisation, Emancipatory Research and Inclusive Research in Learning Disability,” *Disability & Society* 16, no. 2 (2001): 200.

⁷⁴ Thomas G. Couser, “The empire of the “Normal”: A forum on disability and self-representation: Introduction,” *American Quarterly* 52, no. 2 (2000): 307.

⁷⁵ See Dan Goodley, *Self-Advocacy in the Lives of People with Learning Difficulties* (Maidenhead: Open University Press, 2000), especially pages 52-61 and 181-184.

to tell stories through video. After all, how can we, as practitioners of community-based media learn to do collaborative work without detailed accounts of actual attempts at collaboration? As practitioners, if we are to learn and to improve our practice, it is essential to take the time to reflect and analyse our experiences. It is also equally important to write about these experiences to allow others to learn from our successes and our failures. I hope this study will fill a gap in this knowledge and encourage others, as Juhasz's story has inspired me to write about it and initiatives such as National Film Board of Canada's (NFB) Challenge for Change⁷⁶ have inspired me to experiment with collaborative media creation for social change. Although the Challenge for Change program ended in the mid 1970s, it continues to guide current projects like the CitizenShift⁷⁷ website that showcases, among many other projects, a video-based project called *This Ability Media Project*⁷⁸. *This Ability* was a collaboration between the Burnaby Association for Community Inclusion and the Pacific branch of the NFB. I will briefly discuss this video project involving people who have been labelled with an intellectual disability in Chapter III: Stories.

My desire was not only to facilitate self-representation but also to build connections by sparking dialogue among members of the People First community and outside the community. I thought making experienced-based videos might even attract new members and advisors because as bell hooks says : “Excitement is generated through collective effort.”⁷⁹ With all of this in mind, I needed an approach to making videos that

⁷⁶ Some of the *Challenge for Change* films can now be viewed from the NFB's website at: <http://www.nfb.ca/playlists/michael-brendan-thomas-waugh-ezra-winton/challenge-for-change>.

⁷⁷ You can visit this website at: <http://www.citizenshift.ca>.

⁷⁸ To watch these videos, go to: <http://citizen.nfb.ca/onf/info?did=1581>.

⁷⁹ hooks, bell, *Teaching to Transgress: Education as the Practice of Freedom*, New York: Routledge, 1993), 8.

would reflect my beliefs and help me reach my goals of using video for social change. Since I wanted to work with people labelled with an intellectual disability, I needed to come up with an approach to working together. I could not have these goals of using video for change while making videos about this group of people; I had to do it with them. The principles of inclusive research with people with learning disabilities by Walmsley and Johnson guided my video making process with People First.

For the purpose of this thesis, I have chosen the term collaborative instead of participatory, supported or inclusive video storytelling. Although Valerie, Susie and I have used the term inclusive filmmaking⁸⁰ in an article we co-wrote about *The Freedom Tour*, I felt that term collaborative filmmaking better described the type of relationship that I strived to have with the People First co-directors. I find that terms like inclusive and participatory feel more passive, as though people have been asked to participate in an event or process that already exists: to “be involved; take part”⁸¹ whereas collaboration evoked the image of working together⁸² to create something new. The term inclusive has both the advantage and disadvantage of being associated with people who have been labelled. When addressing an audience from within the field of disability studies, it may be an advantage to use this term to hint at the involvement of people who have been labelled to assist other researchers or community filmmakers like me trying to find collaborative work that has been done specifically with people who have been labelled

⁸⁰ Josée Boulanger, Wieszmann, Susie, Wolbert, Valerie, “The Freedom Tour: An experiment in inclusive filmmaking” in *Living the Edges: A Disabled Women’s Reader* ed. by Diane Driedger (Toronto: Inanni Publications & Education, 2010), 305.

⁸¹ Source: <http://oxforddictionaries.com/definition/participate>.

⁸² The Merriam-Webster, “Collaborate”: “Origin of collaborate: Late Latin *collaboratus*, past participle of *collaborare* to labor together, from Latin *com-* + *laborare* to labor. First Known Use: 1871,” <http://www.merriam-webster.com/dictionary/collaboration>.

with an intellectual disability. On the other hand, when trying to reach an audience beyond the disability community, using the word “inclusive” might limit the interest to people already working in the field of intellectual or learning disabilities. A similar logic influenced the choice of *The Freedom Tour*⁸³ as the title for the film. Although collaboration is a very nice word, it can mean many different things hence the importance of writing about the process:

The fact that people with learning difficulties usually need allies or supporters to enable them to undertake research [research is an important aspect of filmmaking] means that they are extremely vulnerable to having their interests misrepresented by others. Research as advocacy [or video storytelling as advocacy] in such a situation puts a heavy onus on non disabled people to act in a disinterested fashion, as they are usually the people who write the words. I would suggest that given the continuing power imbalance between people with learning difficulties and their allies, the position of research [or video] as advocacy is less straightforward than debates in the disability studies literature would suggest.⁸⁴

The process of collaborating with people who have been labelled with an intellectual disability does raise many questions, as Couser also noted above, in terms of power imbalances between allies like myself and people who have been labelled, like the People First members with whom I worked collaboratively. Furthermore, I openly positioned myself as an insider, as a sibling, and an advocate. It has been my intention to take the time to write about and reflect upon the collaborative work I did with People First

⁸³ I was very aware that disability was not exactly considered a sexy topic. I assumed that most people would not be actively searching for short videos or documentaries on the topic of disability or made by people labelled with intellectual disabilities. The title *The Freedom Tour* had the advantage of not naming disability or intellectual disability, thereby allowing people outside the disability community to stumble upon it quite by accident.

⁸⁴ Jan Walmsley, “Normalisation, Emancipatory Research and Inclusive Research in Learning Disability,” *Disability & Society* 16, no. 2 (2001): 201.

members to make *The Freedom Tour* and to refer, when needed, to the *Label Free Zone* video making process. Thus, I have tried to answer some of the questions raised by the imbalance existing between labelled self-advocates and a non-labelled filmmaker. This chapter has outlined the background literature review and project review I had done prior to beginning my work with People First self-advocates. It has also outlined my preoccupations and assumptions about people labelled with an intellectual disability and the goals I hoped to achieve by collaboratively making video stories with people so-labelled. The next chapter will describe the methodological approach I have chosen to tell and reflect upon my experiences of working collaboratively with people labelled with an intellectual disability.

Chapter II: Methodology

In this chapter, I will discuss the methodological approach I have chosen to describe my experience of video storytelling with people labelled with an intellectual disability. I hoped to discover the value of collaborative approaches while also gaining a better understanding of its limitations. I hoped to learn how to become a better practitioner so that I may contribute to the deconstruction of the category “intellectual disability.” To do so, it would be necessary for me to revisit my childhood and step back from my own experience of having a brother who is labelled with an intellectual disability.

How do I Know?

“You have to live it to *really* understand it,” my mother has always said. Although living through an experience is not the same as witnessing or learning about one, we also know it is impossible for us to live through every experience in life and I doubt that many people would want to either. For those of us who have not lived through institutionalization nor lived with the stigma of labels, how can we gain a better understanding of these lived realities? Experience-based stories such as autobiographies, auto-ethnographies, personal narratives and life stories allow us to see situations through the eyes of the people telling the stories. As readers or audience members, these stories invite us to enter the subjective logic of the storyteller and to engage with them as “someone capable of self-reflection and self-representation, someone capable of life

writing.”⁸⁵ While doing my research, I intentionally searched for these personal stories by survivors and self-advocates to help me imagine what people had experienced in institutions and group homes. I was naturally drawn to these first-hand stories by survivors but in the back of my mind I always had lingering doubts about this preference. Were these stories be just as valuable as historical texts or theory? I knew these stories were important but how could I explain it? As I read people's stories of survival, I imagined how I would have reacted in their situation. I also knew that my brother could have stayed in the hospital had he not been adopted.

As a storyteller, I was learning that experience-based stories including autobiography and auto-ethnography created an opportunity for me to question my assumptions and my actions in relation to culture:

When someone is asked to tell their life story or to talk about particular personal experiences and perceptions – whether as an informant to a research project or in any other social setting – they are being given an opportunity to create an identity, a particular self which they may go on to develop and further live out (see Ricoeur, 1980). In social life generally we constantly story our lives in different ways, linking different events, experiences and perceptions, leaving different gaps and using different words and metaphors, in order to fit specific contexts, purposes and audiences.⁸⁶

Although I have consulted with the five co-directors with who I am worked to make *The Freedom Tour*, I have been the primary informant in this research study. I intentionally chose to adopt a similar approach of telling an experience-based story to share my experiences as I had encouraged People First members to adopt for their videos: “You are

⁸⁵ See Michael Bérubé, “Autobiography as Performative Utterance,” *American Quarterly* 52, no. 2 (June 2000): 341.

⁸⁶ Pat Sikes and Ken Gale, “Narrative approaches to Education Research,” *Research in Education (Resined)*, (2006). <http://www.edu.plymouth.ac.uk/resined/narrative/narrativehome.htm>.

the expert on what you've experienced,” I would tell them continuously. However, it was much easier to ask other people to do this than do it myself. Writing from personal experience was something new for me. I naïvely assumed that it would be relatively easy. I should have doubted this assumption since I had previously explored the idea of making an autobiographical video about being an adoptee but had never followed through. Too much self-doubt had set in: What would people think if I started making videos about myself? How could my perspective be of interest and of use to others? I felt that it was too self-indulgent and my energy should be used for more important things like working with people who didn't have the equipment and the know-how to make such videos.

Working with People First members has changed my view on experience-based storytelling. How could it be good for them yet not for me? Was telling stories from experience only acceptable for people who were marginalized? I was afraid since I did not know if it was ok for me to devote time and effort to do this. Regardless of my worries, I could not continue espousing the importance of “speaking from experience” if I was too chicken to do it myself. I needed to take same risks that I was asking others to take by putting their personal experiences up for scrutiny and criticism. By looking at it this way, I saw that it went beyond the fear of being perceived as self-indulgent; this was about integrity. Perhaps by writing from experience, I would gain a different understanding about it. *The Freedom Tour* and the videos made for the *Label Free Zone* were their stories: this thesis is told from my standpoint.

The Goal of this Study

The goal of this study is to gain some insight, through the process of writing an

auto-ethnography, into my experiences of working collaboratively with people who have been labelled in making *The Freedom Tour* and the *Label Free Zone* videos. By revisiting my experiences, I discuss and question some of my assumptions and beliefs about intellectual disability, the system that is meant to provide supports and experience-based storytelling and collaborative approaches to making video. It is also an effort to describe and explore some of the ethical and theoretical implications of collaborative approaches as well as the value of experience-based storytelling. It is a necessary exercise as a practitioner of collaborative video storytelling approaches with labelled people to take a certain distance from my work to recognize some of its limits as well. I struggled for so long to give a name to my methodology. It never occurred to me that I was going to write an experience-based or autobiographic story.

I have asked and supported so many people to write about their experiences, to share their personal stories but I had never done that myself. It is only right to put myself through this process of making sense of my life experiences and my practice as a media activist. I think this will also help me to become a better collaborator when working with others to tell their stories, especially when considering risks and consequences to the storyteller and to the people with whom they have relationships. How did I put into practice theories of participatory video making and inclusive research methods? Which other theories propelled our work of collaborative filmmaking? Which theories can help me and others wanting to use these approaches in future projects whether they are in an academic or community context? In an article written about participatory video projects like the NFB's *Challenge for Change*, Burnett warns that “there has been a lack of critical

and evaluative work done on the videos themselves, although there are many descriptive examples that end up justifying the use of video as a tool of community development and consciousness-raising.”⁸⁷ Further, he says that “very little research time is spent by video-makers on the issues of empowerment, participation, democratic control, and communication...”⁸⁸ Hopefully this study will address some of Burnett's concerns.

Since I have finished working with People First members to create *The Freedom Tour* and the *Label Free Zone*, I have discovered interesting uses of multimedia and autobiographical storytelling like Multimedia Profiling (MPP)⁸⁹ by Acting Up in the UK, Trans-Active and MultiMedia Advocacy.⁹⁰ As I visited their websites and read through any literature I could find about these projects, I saw that some of their objectives were similar to mine in terms of searching for ways to facilitate self-representation and self-expression and to create connections. MMP's focus was on communication while the Trans-Active Passport project aimed to bring labelled and non-labelled students together through the creative process of preparing a multimedia product as a tool for transitioning to young adulthood. These recent developments were geared towards using media as a tool for individual advocacy whereas I was drawn to a collective approach to advocacy.

Despite this fundamental difference, I wanted to learn more about multimedia profiles. They appeared to be an interesting tool for people facing barriers to communication. I wanted a detailed description of the process of making these profiles.

⁸⁷ Ron Burnett, “Video: The Politics of Culture and Community (1996),” in *Challenge for Change: Activist Documentary at the National Film Board of Canada*, ed. Thomas Waugh et al., 73-102. (Montreal & Kingston: McGill-Queen's University Press, 2010): 369.

⁸⁸ Ibid, 373.

⁸⁹ For more information, go to Acting Up's website: <http://www.acting-up.org.uk>.

⁹⁰ See how the Rix Centre in the UK explains the use and value of multimedia at an individual level: <http://www.multimediaadvocacy.co.uk>.

Although a report by Grove mentioned that “[c]onsent is negotiated with the person, through careful reading of their behaviour and responses” and the “user is actively involved right from the start, in making decisions about the content of the files, in creating and selecting material such as photographs and video, and in determining access,”⁹¹ the author does not explain or describe what “careful reading” or “actively involved” means. In a review of Acting Up’s work with Kingsgate Resource Centre, a manager involved in the project commented: “Multimedia... [is] the human face on all the paperwork. I feel, as a social worker, that I don’t lose sight of the people. Multimedia Profiling slaps you in the face with the reality of people and real needs.”⁹² In an article entitled “Multimedia Techniques”⁹³ published in *Planet Advocacy*, McAleese places the emphasis on process and on a person-centered approach. The author says that the strength of multimedia is that “the client” can communicate their experience directly, it does not only have to appear in a staff case study or report. The article also offers some practical tips of using multimedia but, once again, there is no description of the process involved.

Discussing Different Approaches to this Study

As I searched for the appropriate methodology, I looked for approaches that would allow me to share my experiences from a personal point of view, to reflect and learn from them and to share this knowledge in a way that would be interesting and accessible to people beyond my peers in the field of disability studies. I found many approaches that

⁹¹ Nicola Grove, “Multimedia Profiling: A person-centered tool for people with profound disabilities,” City University, 2003. <http://www.acting-up.org.uk>.

⁹² Mel Wright and John Ladle, “Speaking up about home-care,” *OPAAL Newsletter*, 2007.

⁹³ Caroline McAleese, “Multimedia Techniques” in *Planet Advocacy: a Magazine About Independent Advocacy*. Published by Action for Advocacy, Issue no 24 (June-August 2008): 6-7. http://www.aqv59.dsl.pipex.com/June_08_Planet.pdf.

seemed to be a good fit. I looked into methods that would allow me to reach my research goals. Self-study, heuristic inquiry and auto-ethnography all appeared to be appropriate to tell about and reflect upon my experiences as the filmmaker/facilitator of *The Freedom Tour* documentary film and *Label Free Zone* website. Despite the flexibility that these methods allow academics to explore personal experiences, I was surprised to learn that despite a recent rise of the use of narrative approaches within the field of Disability Studies,⁹⁴ these methodologies remain on the fringes.

According to Patton, heuristic inquiry has its disciplinary roots in humanistic psychology.⁹⁵ A heuristic approach is essentially “using experience to learn and improve.”⁹⁶ According to Moustakas, who developed this method, the researcher must have an intense interest in the phenomenon and he or she must have co-researchers who share an equally intense interest in that same phenomenon.⁹⁷ Moustakas identifies six steps to heuristic research: initial engagement, immersion, incubation, illumination, explication and culmination in a creative synthesis. “Likely sources of data include personal documents such as notes or journals, interview notes and transcripts, poems, and/or artwork. Data analysis consists of thorough discussion, introspection, and thought (immersion and incubation) until themes and meanings emerge.”⁹⁸ Although my research does have many similarities with Moustaka's heuristic inquiry, I didn't feel a connection to

⁹⁴ Smith, Brett and Andrew C. Sparkes, “Narrative and its potential contribution to disability studies,” *Disability & Society* 23, no. 1 (January 2008): 24.

⁹⁵ Michael Quinn Patton, *Qualitative Research & Evaluation Methods*, (London: Sage Publications, Inc., 2002): 132.

⁹⁶ <http://www.learnersdictionary.com/search/heuristic>

⁹⁷ Michael Quinn Patton, *Qualitative Research and Evaluation Methods*, (London: Sage Publications, Inc., 2002): 107.

⁹⁸ Wall, Sarah, “An autoethnography on learning about autoethnography,” *International Journal of Qualitative Methods* 5, no. 2 (2006): 5.

it. The idea of following six steps put me off. For Sarah Wall they strike her “as quite idealistic and abstract,”⁹⁹ perhaps that is why this approach did not “speak” to me or compel me to use it.

According to Patton, auto-ethnography has its disciplinary roots in the literary arts. “How does my own experience of this culture connect with and offer insights about this culture, situation, event, and/or way of life?”¹⁰⁰ is a question an auto-ethnographer will ask. Auto-ethnography is a development in ethnographic writing that stems from a postmodernist position that questions the truth-claim of any method of enquiry. “The core of postmodernism is the doubt that any method or theory, discourse or genre, tradition or novelty, has a universal and general claim as the 'right' or the privileged form of authoritative knowledge.”¹⁰¹ For me, this doubt has opened the door to experimenting with a new way of writing. Just as the personal experiences of institutional survivors served as the main source of information for *The Freedom Tour* documentary, I wanted to use my experience of making the film and subsequent videos as the primary source and object of analysis.

I discovered auto-ethnography through communications scholar Carolyn Ellis, thanks to an article by Sarah Wall. When I finally received my copy of Ellis's book *Revisions* and read, “My goal is to turn the narrative snapshots I have written in the past into a form more akin to a video—a text in motion¹⁰² - one in which I drag and drop in new

⁹⁹ Ibid, 5.

¹⁰⁰ Michael Quinn Patton, *Qualitative Research and Evaluation Methods*, (London: Sage Publications, Inc., 2002): 132.

¹⁰¹ Richardson, Laurel, “New writing practices in Qualitative Research” *Sociology of Sport Journal* 17, no. 1 (2000): 15-16.

¹⁰² Carolyn Ellis, *Revision: Autoethnographic Reflections on life and Work*, (Walnut Creek: Left Coast Press Inc. 2009). Ellis cites Davies and Davies (2007) as using the term “texts in motion”: 303.

experiences as well as revised interpretations of old storylines, then reorder them and thus restory them,”¹⁰³ I immediately connected with her approach to writing and her attempts at describing the work of an auto-ethnographer. She offered no concrete steps to follow. In fact, she likened it to being sent “into the woods without a compass”¹⁰⁴. This resonated with how I felt whenever I used collaborative approaches in making video stories. Although the idea appears to be straightforward, create a video story based on personal experience or write an auto-ethnography about my experiences, the process itself is far from it. There are *always* moments of anxiety and doubt with such open-ended and personal approaches but, that is where I feel most at home.

Who would interview me to learn more about the process of making *The Freedom Tour* and *Label Free Zone* videos? To go into such great detail into these experiences would take a lot of time and effort (as I have learned). Who else would ask me to reflect upon my own experience of disability and how it has played a role in my work and my studies? My personal observations would simply have been lost had I not decided to write about them. As I entered the process of making videos with self-advocates, I was an “outsider” as a community filmmaker and an insider as a sibling. This particular perspective had its advantages and disadvantages which I will discuss throughout this study.

In both auto-ethnography and heuristic inquiry, the researcher should speak from her or his own perspective, situate her or himself as part of the process, write reflectively and choose a creative form of representation. Both of these methods would allow me to

¹⁰³ Carolyn Ellis, *Revision: Autoethnographic Reflections on life and Work*, (Walnut Creek: Left Coast Press Inc. 2009), 13.

¹⁰⁴ Sarah Wall, “An autoethnography on learning about autoethnography,” *International Journal of Qualitative Methods* 5, no.2 (June 2006). http://www.ualberta.ca/~iiqm/backissues/5_2/html/wall.htm.

question “Who knows?” and “Who's knowledge is valuable?” Both would allow me to represent my research as a narrative. “While narrative does not yield absolute truth, it can transport narrators and audiences to more authentic feelings, beliefs, and actions and ultimately to a more authentic sense of life.”¹⁰⁵ I finally chose to name my approach auto-ethnographic. I felt more comfortable with the flexibility and arts-based approach rather than the more linear approach proposed by Moustakas. Autobiographical, personal narrative and auto-ethnographic methods can make research and knowledge sharing accessible to more people. Could a person with a so-called intellectual disability use these methods to write their own Master's thesis some day: why not?

Choosing Auto-Ethnography

Ellis says that “autoethnography does not proceed linearly,”¹⁰⁶ is complex and is not conducted according to a special formula. Diving into unknown methodological territory is not without its risks especially since there does not seem to be a correct way to write an auto-ethnography. However, with its roots being in the literary arts, the approach at least is similar to the storytelling approach used to create *The Freedom Tour*, as well as the video stories developed for the *Label Free Zone* website.

There is a lot of questioning about the ethics of writing about ones own experiences because as we do, we inevitably write about other people. For this reason, writing an auto-ethnography was much harder than I first thought. It presented many ethical questions that had to be resolved during the process of writing. By choosing this

¹⁰⁵ Elinor Ochs and Lisa Capps, “Narrating the self,” *Annual Review of Anthropology* 25, no. 1 (1996): 23.

¹⁰⁶ Ellis, Carolyn, *Revision: Autoethnographic Reflections on life and Work* (Walnut Creek: Left Coast Press Inc. 2009), 119.

methodology, I “fell” into ethics: I could not just address the ethics of the study in this chapter of methodology, it intertwined with the stories as I told them. I did not realize that auto-ethnography would take me down that path, but I am happy that it has. I had been searching for an approach to ethics that I would feel connected to and during the process of reading Ellis's *Revision*¹⁰⁷ and writing these stories, I discovered relational ethics through the work of Bergum and Dosseter.¹⁰⁸ The themes of mutuality and engagement in relational ethics helped me to think about the type of collaborative relationship I was striving for as a filmmaker but it also helped to think through the relational implications of experience-based writing. Read Paul describes mutual respect and engagement, central themes of a relational ethic:

Respect is described as interactive and reciprocal, with an emphasis on respect for and acceptance of difference. In coming to mutual respect, there is a need to be both respectful of others and also respectful of oneself. The theme of engagement implores the cultivation of a sensitivity that promotes authentic connection. True presence, personal responsiveness, and empathy are key components of engagement.¹⁰⁹

Ellis speaks of auto-ethnography as a description of experience that is done by paying attention to emotions as they were felt or lived and by using evocative language.¹¹⁰ As this study is my first experience with this style of writing, I found it difficult to balance

¹⁰⁷ See Carolyn Ellis *Revision: Autoethnographic Reflections on life and Work* (Walnut Creek: Left Coast Press Inc. 2009) and Carolyn Ellis, Tony E. Adams & Arthur P. Bochner, “Autoethnography: An Overview,” *Forum Qualitative Research* 12, no. 1, art. 10 (January 2011). <http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095>.

¹⁰⁸ See Vangie Bergum and John Dosseter, *Relational Ethics: The Full Meaning of Respect* (Hagerstown: University Publishing Group, 2005).

¹⁰⁹ Linda Read Paul, RN, MN, CHPCN (C), “Relational Ethics: The Full Meaning of Respect: A Book Review.” http://www.phen.ab.ca/library_books/docs/Relational_Ethics.pdf.

¹¹⁰ Carolyn Ellis, *Revision: Autoethnographic Reflections on life and Work*. (Walnut Creek: Left Coast Press Inc., 2009).

the evocation of emotion without exaggerating or at the risk of sounding melodramatic. How could I describe moments that were felt deeply with the limited experience I had with this genre of writing? The uncertainty I felt when I first began to write was a very real obstacle. I was afraid of heading in the “wrong direction” and risk not getting my degree. On the other hand, I also wanted to use this personal writing to avoid adopting an approach that would be more “abstract, jargonistic and difficult to read”¹¹¹. The latter would certainly not lend itself to building connections and fostering empathy: it would maintain the distance between stories written by self-advocates and academics. I was also aware that by writing this, I had the potential to benefit from my experience of working collaboratively with people who have been labelled in ways that were inaccessible to them. Since post secondary education was off-limits to people who have been labelled, I was the only one who could gain in authority by way of acquiring a Master's degree. All of this made me wonder if self-advocates told “personal stories” while researchers wrote “auto-ethnographies?” Personal stories, life stories, autobiographies, personal narratives, auto-ethnographies: these terms pointed to work that shared many similarities yet had very different connotations.

Relational ethics with its emphasis on the impact of decisions and actions on relationships helped me to acknowledge the primacy of protecting relationships when writing about ones own experiences. The most difficult part of writing these stories has been the moment when I am faced with reading it to a person named in one of my stories. I did not realize, until I actually had to do it, how uncomfortable it might make me feel. I

¹¹¹ bell hooks, *Teaching to Transgress: Education as the Practice of Freedom* (New York: Routledge, 1993), 64.

read about Carolyn Ellis' discomfort but, to be honest, I had to do it to understand it. As I read passages out loud, I felt a strange sort of embarrassment. It was very difficult to read some of the stories to co-directors and my family because I saw how my words took on an entirely different meaning now that the person was listening to me. I saw how I lost control of the meaning of my words and that they could be interpreted in ways that I had not intended. I do not think that this anguish will ever leave me, I simply have to live with it. Sarah Wall talks about the anxiety she felt when writing an auto-ethnography about her experience of adopting a child: "I had a persistent and significant sense of anxiety about the tension between proceeding with an academic project and telling a story about my life that was inextricably intertwined with my son's."¹¹² She has yet to publish her auto-ethnography. The anxiety I have experienced while writing these stories was also caused by the realization that it was impossible to tell some stories (or portions of stories) strictly using the "I". I had not realized how complicated it would be to tell these stories without using the "we" in certain situations. This was very problematic since I had promised People First of Canada that I would be speaking strictly on my own behalf and from my own perspective but how could I pretend that Valerie, Dave, Kevin, Mark and Susie were not there? As an imperfect solution, I have been careful to use the pronoun "we" only in descriptive situations such as "As we arrive, the sky is beautifully clear with a few low wispy clouds and soft but consistent wind." I had to be careful not to use "we" to avoid speaking for others. This was of utmost importance since I am strong believer in the "nothing about us, without us"¹¹³ slogan found in much of the People First literature and

¹¹² Sarah Wall, "Easier Said than Done: Writing an Autoethnography," *International Journal of Qualitative Methods* 7, no. 1 (2008): 49

¹¹³ James Charlton, *Nothing About Us, Without Us: Disability Oppression and Empowerment* (London: University of California Press, 1998), 3. Charlton writes: "I first heard the expression "Nothing About

the disability movement at large.

Taking my cue from People First self-advocates, I have used autobiographical approaches to share my personal experiences and my knowledge. I used the same approach to video storytelling, asking them to speak from their perspective, using their own words to tell about lived experiences. My approach is autobiographical in the sense that I have included a lot of background information about myself, my life. It is auto-ethnographic in the sense that I hope to answer the question “How does my own experience of disability and self-advocacy culture offer insights into the collaborative approach to video storytelling with/by people who have been labelled?”

Stimulated by the progress of the disability rights movement, disability autobiography is more likely to explore the positive ways in which identity and life narrative are shaped by disability, the ways in which disability may *create* culture. (And, in a sense, self-representation by people with disabilities itself constitutes a form of disability culture.)¹¹⁴

Although I do not presently identify as a person with a disability, as a sibling growing up with a brother who has been labelled with an intellectual disability, I have learned to adapt quickly to different people's styles of communication and ways of being. “The unknown” acts as a magnet for me: I am pulled towards people and situations about which I know very little. I see these possible encounters as opportunities to learn something new. Although my desire is to connect with people, I realize that it is not always possible: some people may not want to engage with me. When people are willing to engage with me, sometimes I do not understand because of my lack of knowledge of

Us, Without Us” in South Africa in 1993”. Further, he says that this slogan “resonates with the philosophy and history of the disability rights movement (DRM), a movement that has embarked on a belated mission parallel to other liberation movements”.

¹¹⁴ Thomas Couser, “The empire of the “Normal”: A forum on disability and self-representation: Introduction,” *American Quarterly* 52, no. 2 (June 2000): 308. Italics original.

the person's culture (which can be disability culture) or a person's particular way of expressing him or herself. I have also learned that it is possible to build meaningful relationships beyond the dependence on words, it just takes more time. Finally, my mind and my heart must remain open when engaging with each new person while accepting the possibility of the failure to communicate.

How Did I Conduct this Auto-Ethnography?

I began the documentary project with the desire to write about it. However, I had not finished my course load and could not go forward with writing a thesis proposal until I had done so. I took many notes at the beginning of the film project with People First members but as it gained momentum, the project soon took on a life of its own. My journal notes became more sporadic, but I still hoped that someday I might have the chance to write about these experiences.

To tell these stories, I used many of the same approaches I used while working with People First members on the film and shorter personal videos. I “worked from an assumption of 'truth' rather than 'fiction' (Webster, 1982) and told a story that cohered with the details of personal experience, my notes, and recollections of others (Krieger, 1984)”¹¹⁵ and referred to proposals, the documentary, transcripts, emails, press releases, newsletters, my personal journals, photographs, sketches, articles written by others about *The Freedom Tour* as well as memory work to weave this into a story.

Before I could begin to write these stories, I submitted a proposal to the Research

¹¹⁵ Ellis, Carolyn, *Revision: Autoethnographic Reflections on life and Work* (Walnut Creek: Left Coast Press Inc., 2009), 106.

Ethics Board (REB) of the University of Manitoba. I developed a two-step consent form¹¹⁶. First, I needed permission from the co-directors to go ahead with writing about *The Freedom Tour* experience. I also had to review all stories in which I named people. The REB also asked me to prepare a letter of agreement for People First of Canada since writing about these experiences also meant that I would be writing about one of their projects.¹¹⁷ Although I have written these stories from my own perspective, there are many occasions in the story where I had to use “we” instead of “I” in the stories of Chapter III. I use “we” to more accurately refer to or describe events and actions in which the co-directors and I collectively participated or contributed.

I sent the co-directors and other participants a copy of the story or stories to review and then met with them in person. I called some people to review stories over the telephone since I could not meet them in person. I was surprised at how well the story review process went using the telephone. I read a paragraph at a time and asked them how they remembered the situation. Had I made a mistake or forgotten anything? Did they want to add something or did they have any questions about the story? Did they prefer that I not include this story at all? In some cases, we had long conversations that led to changes and additions. In other cases, participants told me that they did not want certain stories included in my thesis and so I left these out. Other participants had nothing to add to my description of the events. When I chose to write about situations that could put a person at risk or in an uncomfortable position with their support staff, support agency or family members, I disguised their identities. I changed their name, their gender and

¹¹⁶ See Annexe 1 and Annexe 2.

¹¹⁷ See Annexe 3.

sometimes I even change the city and other details. I did this to allow myself the freedom to write about situations that demonstrated some of the social conditions under which labelled people's lives continue to be controlled outside institutions. Although my approach was auto-ethnographic, it involved nonetheless consulting with many people to ensure that they agreed to be included in the study. Consultation also give them the opportunity to make corrections and ask questions that might help better describe situations in which they were involved.

The stories I have chosen to share with you in Chapter III: Stories evolved in my mind since I first set out to talk about my filmmaking experiences with members of People First. Writing this thesis has been a very long process. Two and a half years have passed since I defended my proposal. Over four years have passed since I finished working on the documentary film and three years have passed since making the personal stories for the *Label Free Zone*. I have worked as a casual support worker for non-profit agencies allowing me to gain knowledge about group homes and other supported living arrangements. I spoke with support workers about some of my ideas on privacy and I witnessed events that strengthened my resolve to talk about my experience of collaborative video storytelling with people who have been labelled.

Since presenting my research proposal, I have moved from the Prairies, where these projects took place, back to Ontario to share a house in the countryside with my parents, brother, grandmother, cousin and my two small children: It was the best solution my family and I could find to avoid sending my grandmother to a nursing home. Although I do not like the negative connotation of “single mother,” I am nonetheless

learning about the experience of being a single parent. For the past two and a half years, I have been immersed into this extended family culture. Re-connecting with my family encouraged me to look at my life history to shed some light on my motivations when working with people who have been labelled with an intellectual disability.

I wrote these stories to bring readers along with me on an unexpected journey of working with self-advocates who have been labelled with an intellectual disability. As a student of disability studies, I tried to make connections between the attitudes and preconceptions commonly held about labelled people and the obstacles the co-directors and I faced as we worked on *The Freedom Tour*.

The Process of Writing an Auto-Ethnography

As we tell personal stories we inevitably tell other people's stories too as Carolyn Ellis reminds us. I had to think about relational engagement and the long term impact of the stories I would tell, and how they might affect my relationship with People First members, with my mother and my brother. As I wrote I realized “a voice is overpopulated with other voices, with the intentions, expectations, and attitudes of others.”¹¹⁸ As I wrote the stories you are about to read in the next chapter, I imagined that you might be a student, a researcher, a self-advocate, a caregiver, a family member, a support worker, an artist, an activist, or an educator. I was conscious, and sometimes *self-conscious*, of all these voices as I wrote. Sometimes, I would ask myself “What would that support worker say if they read this story? What if they recognized themselves?” or “What would that

¹¹⁸ Torill Moen, “Reflections on the Narrative Research Approach” *International Journal of Qualitative Methods* 5, no. 4, (December 2006): 3.

participant say if he read this part?” After thinking about this for a while and discussing my concerns with People First co-directors, I have re-worded certain passages and in other instances I have omitted entire stories. The issue of voices has been the most difficult because of my insider position as a sister. I know many people working in so many different positions within the community and I have imagined the reaction that these people might have if they read my thesis. I have agonized about my duty to be truthful in telling about my experiences and the consequences of telling them. Who do I finally owe explanations to for my choices? I think, in the end, I have to feel comfortable defending what I have said to people who have been labelled. My stories cannot do harm to this group of people and if there was a risk that they could do harm, I have removed them. Even as I say this, I continue to have doubts.

As a sister, I would like to try to answer the question: Are there any benefits to having a sibling with a disability? “Conceptual models of families too often view children with disabilities as stressors rather than as family members.”¹¹⁹ When researchers obtained results that pointed to positive outcomes of having a sibling with a disability they were interpreted through a lens of pathology: “Those seemingly positive findings must be caused by guilt experienced by the siblings that inhibits their expression of negative feelings.”¹²⁰ In other words, as a sibling of a person labelled with an intellectual disability, I felt so guilty about “my poor little handicapped brother,” that I could not express my “true” feelings about him. This is when I think of Couser and his idea that, “Autoethnography may offer a way out of this bind for life writers, insofar as it

¹¹⁹ Zolinda Stoneman, “Siblings of Children With Disabilities: Research Themes,” *Mental Retardation* 43, no. 5 (October 2005): 347.

¹²⁰ *Ibid*, 347.

speaks of disability as a condition that is affirmative rather than catastrophic, *defining* rather than *confining*.”¹²¹ In an other study on family and sibling relationships, it said that sisters “used their connections to their siblings as a means to elevate themselves morally and to resist dominant sociocultural discourse that devalues people with disabilities (and their family members).”¹²² Did I (am I) using my relationship with my brother to take the moral high ground? The presence of a brother with a disability *does* put a strain on a family because he was not expected nor accepted by society. “It is possible that some of the negative effects attributed to sibling caregiving in previous studies actually were caused by pervasive childhood strains associated with poverty (McHale & Gamble, 1989; Stoneman et al., 1988).”¹²³ The negative effects here were being blamed on disability when in reality, poverty and the lack or nonexistence of publicly-funded supports for families was most probably the cause for stress. When talking about families in the late 1800s, Mills states that “For the wealthy, though, this [a disabled child] was simply a private trouble, not a public issue (Mills, 1959).”¹²⁴ Money ensures access to supports that are needed for a child or for an adult, like my brother, to do things that most 35 year old men would expect to be doing here in Canada. Would money eliminate the social distance created by a medical understanding of intellectual disability? A young woman with a physical disability living in her own studio with the supports she required, explained her

¹²¹ Thomas Couser, “The empire of the “Normal”: A forum on disability and self-representation: Introduction,” *American Quarterly* 52, no. 2 (June 2000): 309.

¹²² Lori A. McGraw and Alexis J. Walker, “Meanings of Sisterhood and Developmental Disability: Narratives From White Nondisabled Sisters,” *Journal of Family Issues* 28, no. 4 (2007): 490.

¹²³ Zolinda Stoneman, “Siblings of Children With Disabilities: Research Themes,” *Mental Retardation* 43, no. 5 (October 2005): 347.

¹²⁴ Steven Noll and James W. Jr. Trent, *Mental Retardation in America: A Historical Reader*. New York: New York University Press, 2004: 46.

situation: “Everyone who comes here to see me is paid to do it.”¹²⁵ Although the matter may be “simply a private trouble” for families as Mills puts it, for the person, whether a child or an adult, the stigma of disability continues to isolate. If my brother had the money he needed to pay for a support worker to accompany him throughout his day to live on his own, to go to work, to attend social activities or to go back to school, would he have unpaid visitors other than members of his family? I have no way of answering this, but I do know that he would be out there, whether he is expected or not.

Stoneman suggests that one way to correct the biases found in research about families with members who have disabilities, is to talk directly to people who experience disability and to “let their voices influence our research questions and how we interpret our findings.”¹²⁶ Speaking directly with people who experience disability is not always possible and that is why stories and testimonies produced by labelled people are so essential. The experience of being a sibling (as opposed to parenting a child with a disability) is a perspective that should not be overlooked for the perspective it may add to our understanding of the social roots of intellectual disability. As a sibling, I have tried to learn not to take other people's comments about intellectual disability too personally, but that has always been very difficult because it is personal, when people are talking about “them,” they are also talking about my brother. As I began to write and to think about my role, it became apparent that I would also have to share some of my experiences as a sibling.

¹²⁵ Laurent de Cherisey, Philippe Pozzo di Borgo and Jean Vanier, *Tous intouchables?* (Montrouge: Bayard, 2012), 28.

¹²⁶ Zolinda Stoneman, “Siblings of Children With Disabilities: Research Themes,” *Mental Retardation* 43, no. 5 (October 2005): p. 347

Evaluating Auto-Ethnography

Laurel Richardson situates auto-ethnography in what she calls Creative Analytical Practice or CAP ethnography, in which she includes many other forms of ethnographic writing such as fiction stories, poetry, drama, performance texts, writing stories and mixed genres. These approaches and forms of representation display “the writing process and the writing product as deeply intertwined; both are privileged. The product cannot be separated from the producer or the mode of production or the method of knowing.”¹²⁷

She also uses five criteria when reviewing such papers 1. Substantive contribution: Does this piece contribute to our understanding of social life? 2. Aesthetic merit: Does the use of creative analytical practices open up the text and invite interpretive responses? 3. Reflexivity: Do authors hold themselves accountable to the standards of knowing and telling of the people they have studied? 4. Impactfulness: Does it generate new questions, move me to write, move me to try new research practices, or move me to action? 5. Express a reality: Does this text embody a fleshed out sense of lived experience?¹²⁸

Following Duncan's lead, I identify the boundaries of my study “using the four facets of time, location, project type, and point of view.”¹²⁹ The time period I have chosen to focus on covers a four year period beginning in 2005. I also chose to include a few stories about growing up with a brother labelled as intellectually disabled to shed light onto some of my attitudes and assumptions as I embarked on my work with People First

¹²⁷ Richardson, Laurel, “New writing practices in Qualitative Research,” *Sociology of Sport Journal* 17, no. 1 (2000): 10.

¹²⁸ Ibid, 16.

¹²⁹ Margot Duncan, “Autoethnography: Critical appreciation of an emerging art,” *International Journal of Qualitative Methods* 3, no. 4 (2004). http://www.ualberta.ca/~iiqm/backissues/3_4/html/duncan.html.

members, and to also refer back to my personal experience with disability as a sibling throughout the narrative found in Chapter III: Stories. The events described took place primarily in the province of Manitoba, but also in Saskatchewan and Alberta. The narrative was written from my perspective as the filmmaker who initiated the collaborative process of making videos with People First members.

Coming back to the idea of many voices, Moen says that “Stories cannot be viewed simply as abstract structures isolated from their cultural context”.¹³⁰ Professionals, doctors, social workers, artists and researchers have socially constructed intellectual disability and it is represented through a variety of forms that have been off limits to people who have been labelled with an intellectual disability. “Truth is a matter of consensus among informed and sophisticated constructors, not of correspondence with objective reality.”¹³¹ My desire is to tell these stories to continue to participate in the social re- or de-construction of the popular notion of intellectual disability that is primarily based on an assumption of difference as pathology and this as a sign of incompetence.

Finally, I chose to represent my findings in the form of a story. I chose this form specifically because it is easier to understand: “on a cognitive level a story is easier for people to remember than is a string of isolated, disconnected facts.”¹³² Furthermore, “Free from discipline-specific jargon and other prohibitive (even elitist) barriers, arts-based representations can be shared with diverse audiences, expanding the effect of scholarly research that traditionally circulates within the academy and arguably does little to serve

¹³⁰ Torill Moen, “Reflections on the Narrative Research Approach” *International Journal of Qualitative Methods* 5, no. 4, (December 2006): 5.

¹³¹ Michael Quinn Patton, *Qualitative Research & Evaluation Methods* (London: Sage Publications, Inc., 2002), 98. Citing Guba and Lincoln, 1989.

¹³² Heather Forest, “Artful Leadership for Creating Positive Social Change: Reflections on an Arts-Based Autoethnography,” *Storytelling, Self, Society* 5, no. 2 (2009): 72. Citing Caine and Caine 1994.

the public good.”¹³³ hooks reminds us that adopting more accessible forms of representation is a benefit to a large population beyond people who have been labelled with an intellectual disability:

And it is easy to imagine different locations, spaces outside academic exchange, where such theory would not only be seen as useless, but as politically nonprogressive, a kind of narcissistic, self-indulgent practice that most seeks to create a gap between theory and practice so as to perpetuate class elitism. There are so many settings in this country where the written word has only slight visual meaning, where individuals who cannot read or write can find no use for a published theory however lucid or opaque. Hence, any theory that cannot be shared in everyday conversation cannot be used to educate the public.¹³⁴

I have attempted to create a story that will allow you to see these experiences through my eyes: “Autoethnography from the point of view of the teller offers concrete and credible information. It is grounded in authentic, embodied knowledge. We cannot viscerally know the inner workings of another. We can only empathize and compassionately attempt to climb into another’s reality through inference language, and vicarious experience.”¹³⁵ In addition: “What matters is the way in which the story enables the reader to enter the subjective world of the teller-to see the world from her or his point of view, even if this world does not 'match reality.’”¹³⁶ I have made efforts to “meet literary criteria of coherence, verisimilitude, and interest.”¹³⁷

¹³³ Patricia Leavy, *Method Meets Art: Arts-based Research Practice*, (New York: The Guilford Press, 2009): 14.

¹³⁴ bell hooks, *Teaching to Transgress: Education as the Practice of Freedom*, (New York: Routledge, 1993): 64.

¹³⁵ Heather Forest, “Artful Leadership for Creating Positive Social Change: Reflections on an Arts-Based Autoethnography,” *Storytelling, Self, Society* 5, no. 2 (2009): 75.

¹³⁶ Ken Plummer, “The Call of Life Stories in Ethnographic Research,” *Handbook of Ethnography*, ed. Paul Atkinson et al., (London: Sage Publications Ltd, 2001), 401.

¹³⁷ Laurel Richardson, “New writing practices in Qualitative Research,” *Sociology of Sport Journal* 17, no. 1 (2000): 11.

Challenges and Limitations of this Study

When I met with Valerie to read a passage from this study, she told me that some of the language was difficult to understand “Well cause I know you're writing that for people who have a higher education than us” at which point I thought: am I really writing this for people who have been through some higher education? And if so, then what good is that? “Once I've defended my thesis, I'd like to make a plain language version of the parts self-advocates might find interesting,” I offered to Valerie, but I still don't feel happy with this.

After I read Dan Goodley and Michele Moore's article about doing disability research, I felt I had to change my approach to writing this study: “We believe that it is a cop-out to point to university criteria for research evaluation as a reason for not pursuing more innovative forms of scholarly activity.”¹³⁸ Their words resonate loudly in my mind. They say what I've been thinking but didn't have the courage to do out of fear of not meeting the requirements for my Master's thesis. Writing my thesis as a story just wasn't good enough a solution, I had to add illustrations to support what I was talking about. My assumption that translating my thesis into plain language would be of interest primarily for those who do not or cannot read was also wrong. Writing my thesis in plain language, which includes illustrations, would benefit, not only many people outside the academic community, but also people within academia by creating a concrete example not just talking about it. Although I acknowledge this should be a credible way of representing my experiences, I have fallen short of meeting these standards and realize that the stories

¹³⁸ Dan Goodley and Michelle Moore, “Doing Disability Research: activist lives and the academy,” *Disability and Society* 15, no. 6 (2000): 877.

about my experiences, although written in conversational English, will not reach many people who have been labelled with an intellectual disability without the assistance of a reader. I would have to work much harder at creating a truly plain language version of my thesis as well as recording an audio version. I would need assistance by people who have been labelled to evaluate this work.

One of the limitations of auto-ethnographic and autobiographical approaches “is the internalization of prejudices, the colonization of minds. Those who accept society’s devaluation of them are less likely to consider their lives worthy of autobiography; stigma tends to silence the stigmatized.”¹³⁹ I was struck by how different this was from my experience of working with People First members. In my work with them, I never got the impression that anyone had been silenced by their fear of not having a story to tell. The people I encountered, from the moment I set up my video camera at the Manitoba Legislature, all knew they had important stories to tell. People just were not listening. My decision to experiment with writing from personal experience came as a result of the work I did with People First members to capture their stories on video. Maybe their courage to speak personally gave me the courage to try myself. Auto-ethnography is limited by my ability and willingness to question my motives and to ask, as Griffith says “ask some difficult, challenging questions”¹⁴⁰ about the work I did. Another limitation is my lack of experience at this type of writing.

In the end, this process of discovery is about the positive ways that my life has been shaped by my personal and professional experiences with people labelled with an

¹³⁹ Thomas Couser, “The empire of the “Normal”: A forum on disability and self-representation: Introduction,” *American Quarterly* 52, no. 2 (June 2000): 307.

¹⁴⁰ Morwenna Griffith, *Action for Social Justice in Education: Fairly Different* (Maidenhead: Open University Press, 2003): 60.

intellectual disability. The experiences I have had the privilege to live and are now sharing with you are as a result of disability. By sharing my personal story and the work I have done with people labelled with an intellectual disability, I hope to contribute to the increasing body of disability-based culture and knowledge. Observing how people react to my brother and to other people who have been labelled, has prompted me to learn a few things about the way humans behave, about the power of ideas, about social control and about fear.

Do the stories help to further destabilize the label of intellectual disability? Do they give you, as a reader some ideas about approaches to working with people so-labelled? Could this study be about the way disability can create culture? I hope so. In this story, I am writing about myself and how I experienced making video stories with self-advocates, what I learned and observed along the way about ethics, access, gatekeeping and consequences, and how this work has changed my life.

Chapter III: Stories

In this chapter, I write an auto-ethnographic story about my experiences of growing up as the big sister to my brother who has been labelled with an intellectual disability. I have chosen to write about my childhood because it has had such an impact on my understanding of intellectual disability and my commitment to finding, what I hope, are respectful approaches to working with people who have been labelled. Following the section on my childhood, I have written about the process of discovery that led me to working collaboratively with People First members to make *The Freedom Tour* and the *Label Free Zone* videos. In the description of my experiences as the filmmaker involved in these two projects, I focus primarily on *The Freedom Tour* project, I use only a few examples from the *Label Free Zone* videos, when necessary, to illustrate situations that presented opportunities to discuss issues access, gatekeeping, and power that had not presented themselves during *The Freedom Tour*. I have mostly made use of the past tense but I sometimes use the present tense as an attempt to going back to that moment as I lived it.

Stories From Being the Big Sister

When I was three and a half years old, my parents adopted my brother Stéphane. Back then, we lived in Timmins, a mining and forestry town in North Eastern Ontario. My father worked in the mines for a few years, but then decided to follow in his father's footsteps and start his own painting business. My mother had her own hairdressing salon

in our basement. I always knew that I had been adopted, so it seemed normal that my new brother would also join the family through adoption. In 1978, my parents flew to Charlottetown, Prince-Edward-Island to pick him up. He was just a year old. The adoption agency wrote up a description of Stéphane explaining that he had spent the first year of his life in and out of the Queen Elizabeth Hospital because of breathing difficulties, colds and a hernia. Otherwise, he was a healthy little baby. My parents brought him home and they soon noticed that he couldn't crawl or sit up on his own. My mother has told me how she used to put him in his high chair and he would slide right through. She tied him to the chair so he wouldn't fall out of it.

My parents didn't know what to think, they were confused but they thought it



Fig. 2. My brother and I in 1980, Family Archives.

would just pass, and that he would eventually learn the things that other babies normally learned. I vaguely remember wondering why he didn't laugh or react much. At sixteen months, he still couldn't sit up and no one could explain why. My parents drove nine hours south to the Toronto's Sick Children's Hospital to try to get some answers. The doctor explained to my parents that Stéphane would be slower in learning. My mother told me: “and he said something else, I don't remember the exact words that he used but that's when we knew it would be for the rest of his life” then she adds, “actually, the only words I do remember is when the doctor asked me, 'Are you

going to keep him?' I didn't know what he meant because in my mind I had already adopted him.” My mother could not give my brother back to the Children's Aid Society.¹⁴¹ In her eyes, he was already her baby, not a pair of pants she bought in a store that didn't fit the way she had hoped.

When Stéphane was a toddler (see figure 2), he would be cry a lot but my mother couldn't figure out what was wrong with him, neither could the doctor in Timmins. To try to find some answers, my mother, my brother and I did a lot of traveling. Sometimes my mother travelled alone by plane with Stéphane. Other times, we took the train to Toronto to go to the Sick Children's Hospital or to the Society for Crippled Children, now known as Easter Seals. I have fond memories of those trips. I loved the traveling and I even liked going to the hospitals. I saw kids who looked very sick but I don't remember feeling scared. I was happy to eat the same food as them: That's when I learned you could put ketchup on fish sticks! Later, we started going to the Children's Hospital in Ottawa because my aunt and uncle lived there and we could stay with them to avoid hotel costs.

As exciting as it was for me as a child to visit all these places, the cost of traveling was adding up and my mother needed to get some help to cover the costs. She wasn't sure who to turn to for this and, with only a grade nine education at the time, she didn't feel very confident about writing a formal letter to the Children's Aid Society. Luckily, my uncle had managed to finish high school at the seminary in Sudbury so he helped her to write the letter. My mother waited and waited for a response but when none was forthcoming, she decided to call Children's Aid: “When we asked them about moral and

¹⁴¹ Children's Aid Societies are publicly funded agencies that are responsible, among other things, for managing adoptions in Ontario.

financial support, the woman suggested that if we were not satisfied, we could return him.” My mother pulls a copy of the letter written by the Children's Aid Society out, and I notice that there is no mention of returning him. “Well, they *were* smart enough to know not to write that down!” she remarked sarcastically. Since my parents never received financial support for the costs of traveling to meet with doctors, my mother came up with some of her own solutions, “to save money on traveling to Toronto or Ottawa, I pretended that Stéphane was still two years old when he was actually four years old, at least this way his fare was free. Nobody ever questioned me about it because he was so small for his age.” I remember that my family and I loved tricking people at Canada's Wonderland who could guess people's age because they always got it wrong with my brother, so we would win prizes. As a kid, I enjoyed watching them get it wrong over and over again until we gave them the right answer.

My mother was very frustrated with our family doctor when she tried to describe Stéphane's severe episodes of weakness. The doctor had never seen Stéphane in one of these states and he wouldn't move forward with any tests or referral to a specialist. My mother felt that he didn't believe her: “I think he thought I was exaggerating.” She didn't know what to do to get the doctor to listen to her. My uncle, who had a super 8 camera back then, suggested he could film Stéphane to show the doctor what these episodes looked like. No one remembers if anyone actually showed the doctor this reel but, we still have it. During a Christmas eve dinner at my uncle's, I sat in the living room with family members and friends watching images of us at the cottage, visiting my grandmother or on a family trip when suddenly this film of my brother walking towards

the camera was projected onto the wall. I felt so uncomfortable when I saw that image. I wanted to stop the projector immediately and I did. It was disturbing to see my brother filmed that way, like he was a thing, a crippled child. He looked like he came straight out of a medical text book. My uncle had made this film to *prove* to the doctor that my mother was telling the truth about his episodes of weakness that she was not exaggerating. The doctor-patient relationship was very different back in the 1970s. Especially for my mother, as a francophone woman with only a grade nine education, her descriptions and explanations would not have had much weight in relation to a male anglophone doctor's opinion.

I wondered if my mother had received any kind of help or support with my brother. She shrugged and then told me about this one time Social Services sent someone to help her with Stéphane because she didn't know how to get him to listen: "They didn't know anything. They sent me a young woman once to help with disciplining Stéphane. If he didn't listen, he had to sit in chair for a few minutes. It didn't work and she stopped coming by. They don't know what they're talking about. Nobody understands. Only other parents understand and even then, some of them don't even understand cause their kids are in care! It's not the same," my mother said with frustration. I remember that my brother's arms were very strong because he crawled with them for a long time before he could walk. Our yard was completely fenced in with 5 foot tall wood planks, but he somehow managed to get himself over this fence! It wasn't long after that incident that I came home from school to find him out in the front yard with a child harness and rope tied to the house somewhere. I don't remember what I thought about this, but I do

remember that the rope had made a few turns around the trees. Maybe that young social worker had dropped it off for her. Doctors and social workers weren't the only ones questioning my mother's knowledge. Many people, including family members, had all kinds of opinions about my brother: "He's too spoiled, he needs more discipline!" "He never listens!" and they had suggestions on what to do about it, "You should place him somewhere with other kids like him" or "He should learn to do that on his own," "You should punish him more," "You shouldn't let him get away with that." Family and professionals were very generous with advice but not so much with support.

My mother said "I didn't realize why Stéphane couldn't understand me when I asked him something like go to your room, put your toys in the bin and come back to the kitchen for your snack. I think I thought he just wasn't listening, I don't know." Like most little brothers, Stéphane would destroy some of my things but one day, I'd had enough. I must have been about eight years old when I came back from biking around the neighborhood with my friend and ran downstairs to my playroom. My father had cornered off a section of the basement and made a big door out of plywood that could be locked. Sometimes it was my "office" to hide top secret maps, at other times it was a classroom, a convenience store and even a hide-out to practice some breakdancing moves. I saw that the door had been left open. I walked in to see my desk turned upside down and my maps and fake cheque books strewn all over the floor. The room was a complete disaster!

I stormed upstairs to tell my mother. My mother had been having coffee upstairs with one of her friends while Stéphane and her friends' two boys were playing in the basement. To me, it didn't look like they had played in there, it looked like a tornado had

swept through it. Since I wasn't getting any help from my mother, I went looking for my brother. Those boys were gone now so he would be the target of my anger. I found him. He was playing in his room like nothing had happened. He looked at me, obviously happy to see me. Well, I sure wasn't happy to see him! I sat down on the floor to look straight in his blue-grey eyes, "I know what you did, you messed up my room, you broke my stuff." He appeared to be completely unaffected by my angry accusation. He just kept playing with his Ernie doll. He was purposely ignoring me, he was testing me again, I could tell: "You understand everything don't you? I know you do. You're just pretending not to understand." He looked away for something more interesting to play with. "Stéphane, look at me!" Finally, he looked at me again. "You've been sent here to test me, you're testing us but you'll never admit it" I said. I thought he must have come from outer space to see how my parents and I would react to him. Every once in a while, I believed that he was pretending to forget things and to not understand others. I was so frustrated at not being able to get through to him. I wanted him to "snap out of it" and start talking to me like everyone else did. I sat there waiting to see if he would "crack" and stop playing his role and blurt out "Ha, ha! Gotch-ya"! Like the adults around me, I began to suspect that my brother was pretending to be the way he was just to get away with things. Luckily, by the time I was eight or nine, this "sent from outer space to test us" theory didn't stand up very well to experience. I had to conclude that Stéphane was simply my brother.

Stéphane and I never went to the same school. Growing up, I never really gave it too much thought. It was just the way things were, he went somewhere else during the day. I don't think it ever occurred to me that we could have attended the same school. I

never had any classmates with disabilities. In high school, there was a group of students that may have had learning disabilities but all the kids just thought they were some kind of delinquents. They never took classes with the regular students, and they even took their recess at a different time.

When I was nine and my brother seven, my mother told me we moved to Ottawa to access better services for my brother and better opportunities for me. Moving to Ottawa meant adapting to a new city, making new friends and adjusting to life without our father since less than a year after moving, he decided to go back to Timmins to his painting business. My mother raised us on her own from that time on. In the national capital, I quickly became aware that I had an accent. My Northern Ontario French stood out when I started my new school: “Are you English?” some of my grade six classmates would ask me. It was simply the way most working class francophones spoke in Timmins: jumping from French to English, it has a name: Franglais. It was both a result of being surrounded by English and a way to sound more intelligent: by adding an English word here and there I could let people know that I knew English, not just French. In Ottawa, this way of speaking, I could sense, gave my friends the impression that I was an uneducated kid from the hinterlands of Northern Ontario. Although looks were important, I realized so was the way I spoke. I had known that before that since, in Timmins, as kids we received “speech therapy” classes to correct our French and make it more acceptable. But back then, I just laughed at those attempts since all my friends and family spoke like me. Now that I was the only kid at school who spoke “French from Timmins.” I wasn't laughing about it anymore. As a twelve year old, I had two choices, adapt to the local spoken

French to fit in or give up and join the English school system.

I decided to try to fit in and worked on adapting my spoken French to sound more like a local. I went on to attend high school at De La Salle in a visual arts program. My brother on the other hand, could not adapt his way of speaking to fit in (although he did see speech pathologists who also tried to correct his way of speaking) so he went to Jeanne La Joie. My mother said it helped parents to get to know each other and to keep in touch so they didn't feel so isolated. As I listened to her, I couldn't help but say something: "But mom, those segregated schools kept him from going to a regular school like all other kids! What did they really learn in segregated schools?" I asked her. "I know they didn't learn much but once our kids had been sent to different schools, us parents no longer kept in touch, we were isolated again. Not only that, our kids were getting teased in the regular schools. It's like they were the guinea pigs for integration. I liked the other school better," my mom said definitively. Jeanne la Joie was shut down during the mid 1990s when major cuts were made to education system in Ontario and to special education in particular¹⁴² and a move to integrate so-called special education students into regular classrooms. "It's not fair that our kids have to suffer being laughed at and left out because other kids need to learn how to be with handicapped people" my mother said with great emotion. I don't make anymore comments. She won't change her mind, we've talked about segregated schools before. As imperfect as so-called integration was, this was about my brother's chance at an education, I thought, not about her as a parent.

¹⁴² See Jordan "Ontario: Canada: Reversing the gains made in special education," (paper presented at the International Special Education Congress, University of Manchester, Manchester, United Kingdom, July 2000) and Charlotte Morgan, "A Brief History of Special Education", *EFTO Voice* 7, no. 2 (Winter 2003).

Stéphane was “integrated” into a regular high school but he was not included in regular classrooms. As my mother had feared, he was sitting on the sidelines looking in. What would it have been like if Stéphane and I had gone to the same school? In my perfect world, he would have taken the dramatic arts program at my high school since he is a very outgoing and expressive person. Instead, he finished high school at the age of 21 armed with a Certificate of Accomplishment (COA) which simply means “he was there.” That got him into a life skills program at the francophone community college but even that program was shut down, and he has attended the same community transition day program since 1999. I finished high school with an Ontario Secondary School Diploma (OSSD) and went on to work and to travel and, eventually, to attend university.

After my parents divorced, my father would visit us in Ottawa once in a while. I remember talking to him about my brother and he simply said that my mother's choice to keep him and that she could have found a place for him somewhere: “Stéphane wouldn't know the difference, he would eventually forget about us and be happy living anywhere.” I was mad because I knew how much my brother missed him since he had left. My brother talked about him all the time. I knew Stéphane wouldn't forget his own family anymore than I would. My father was convinced that my brother was not like other children, that he was fundamentally different, but I knew he was wrong and that my brother would have the same feelings as any other child that is abandoned. I could never understand how my father, who had spent seven years with his son, had never noticed that. That is how I came to understand that just knowing a person with an intellectual disability is not enough to see past the labels.

My mother would sometimes say “It's too bad you don't have a brother or sister you can talk to or count on” It's as though she feels I've been cheated of a having a “normal” sibling. I always remind her that I do have a brother and that, “No, I never felt like an only child.” I always think about it the other way around, if Stéphane was not who he is, I might never see him and even if he was considered normal and lived near by, who says he would be a brother “I could count on?” I was always aware that our family was not “normal”: single parent home with two adopted kids, one with a so-called intellectual disability. The talk shows did a good job of reminding me that I was from a broken home.

Although my mother generally speaks negatively about social workers and doctors, she does remember a few good ones along the way. But usually, these social workers didn't last very long, they retired or they moved on to other jobs or other times to new positions within the same agency. When she talks about these people her face lights up and she says how nice they were, that they understood, that they believed her and treated her and Stéphane with respect. What she remembers most was their attitude towards her and Stéphane: “Stéphane must have been about six years old by the time a psychologist from the Ottawa's children's Hospital told me that Stéphane *could* understand but only if I asked one thing at a time. I didn't know that back then. It would have spared him and I lots of stress and frustration. I didn't have Google to look it up you know.” It seems so simple: they were nice to her and to my brother. They listened and spoke respectfully. As the big sister, it's easy for me to laugh at many of the things we went through, I wasn't responsible for raising my brother, he was there next to me growing up. My frustrations stemmed more from other people's reactions to my brother.

Still today,

when I meet new people and they ask me about having any brothers or sisters.

“Yes, I have a younger brother”

“Does he work?”

“He goes to a day program for people labelled with an intellectual disability”

“Oh, what does he have?” As soon as the label “intellectual disability” pops up, it taints everything. I no longer have a brother, I have an object of curiosity or mystery. I shift into defense mode, ready to correct their assumptions.

My brother has always loved buses, we would even go for a ride once in a while just for fun. I remember this one time when I was about sixteen and so he must have been thirteen or fourteen. He was chatting away very loudly, as he always does:

“Il fait beau, hein?”

“Oui, il fait beau aujourd'hui.”

“Whoa, il va vite l'autobus!” and as a young woman stepped onto the bus:

“Elle est belle, elle!” and in his way of speaking that is often difficult for others to understand.

I became aware of people staring at us, one woman in particular. I could feel her eyes on us. I felt anxious and I suddenly wanted my brother to stop talking so that people would stop staring. Why did people always have to stare? My brother didn't feel uncomfortable, he was talking and having a great time “cruising” around the city on the bus with his big sister. I knew I couldn't ask him not to speak so loudly. He might do it for a few seconds

then forget and start up in his usual volume. I had two choices as I saw it: get off the bus or relax and enjoy the ride. Getting off the bus would kill my brother's fun and plus, how would we get back home? Staying on the bus meant that I just had to stare back at that woman. If people stare today, I look right back at them and smile, sometimes I even wave and say "hi" to get their attention. Some people smile back and say hello, some even engage with us while others turn away quickly trying to pretend they were never looking in the first place.

I act as a buffer and a bridge. When people are first getting to know my brother, I might help out by interpreting for the new person because they usually have a hard time understanding him. At the same time, I am taking mental notes of their assumptions and make corrections in sometimes subtle, and other times not so subtle ways. Last Sunday while having lunch at a local restaurant, a waitress asked me "Would they like some ketchup?" as she pointed to the next table where my brother is sitting with his friend. I replied "I don't know, ask them."

Then, I wondered how my mother felt about other people's attitudes, so I asked her. "When Stéphane was a baby, it made me feel sad because family members didn't come up to play with him like they did with the other babies and kids in the family. He was just sitting there, he didn't get the same attention."

"And what about going out in public", I asked her, "how was that when he was little?" "People always look, especially when he talks but I never felt embarrassed or shy about him. It makes me laugh sometimes because people are so uncomfortable, it makes me

laugh. That's the way I am now. It doesn't bother me.” It may not bother her but it has always remained a topic of conversation: how people interacted with my brother. In most situations, Stéphane doesn't give people a choice, he places his hand on their shoulder, gives them a strong hand shake, sometimes even a hug if he suspects he might know you. He's so genuinely friendly, it's hard *not* to engage with him.

Searching for My Place in the World

Zooming many years ahead and after travelling and working in all kinds of places to learn from “the university of life,” as a fellow tree planter from Peru had put it, and tired of breaking my back and then working for measly wages, I finally decided it was time to go to university. I chose to study communication after hiring a student to edit a short video I had made with friend of mine. I immediately saw video as a powerful tool to communicate ideas and tell stories. In short, I went to university to become a social activist. It may sound naïve but that was my plan: go to university, learn about communications and media production in particular, and do good using those tools. While I studied at the University of Ottawa, I was most interested in grassroots media initiatives that aimed to give non-professionals access to the knowledge and tools required to speak from their own experience through video. Although I had always used drawing and painting as my method of expressing myself artistically, I had trouble seeing how these mediums could compete with video in terms of its ability to give the illusion of reality and of its capability to reach people regardless of their level of literacy. Although video was still complicated to make, I continued to favour it over other media as an accessible

and powerful means for self-expression.

The approach I favoured was most commonly referred to as participatory video. I first learned about participatory video in the context of a course on communication and international development. Although, I read about the dangers of participatory video projects reproducing the same power imbalances and impositions from rich countries to poor countries as more traditional uses of communication for development. Projects that I found particularly inspiring were Video SEWA,¹⁴³ a cooperative created by the Self-Employed Women's Association (SEWA), The National Film Board of Canada's Challenge for Change - Société Nouvelle. The goal of this programme was to put filmmaking in the hands of regular Canadians. Challenge for Change projects focused on isolated communities and used film and later video to stimulate social change and community development. The most famous project took place on Fogo Island in Newfoundland. It is now sometimes referred to as the Fogo Process and has inspired many indigenous media projects.¹⁴⁴

Once I finished my studies in communication and gained practical experience making short videos as well as a documentary on the social impacts of the cut-flower industry in Ecuador, I moved to Manitoba to work at an international children's film festival.¹⁴⁵ During that time, I had the joy and privilege of teaching media production to students throughout the province in both French and English. My most memorable workshops were when students made videos based on their personal experiences. At times I felt less than capable to support students in their storytelling efforts like when suicide

¹⁴³ See <http://www.videosewa.org>.

¹⁴⁴ For example the Kayapo Video Project in Brazil: <http://www.comminit.com/global/node/1638> and Through Navajo Eyes in the United States.

¹⁴⁵ Freeze Frame, The Media Arts Centre for Young People: <http://www.freezeframeonline.org>.

and gang membership came up in a northern Native community. I reached out to local resources only to learn that there was very little available to students who wanted to talk about serious issues. I saw how video and storytelling captured students imagination when teachers were surprised to see students participating and staying in the classroom instead of roaming around in the hallways. Although I did fear negative reactions from the school's administration in regards to the sensitive nature of the topics students chose, they were very supportive and gave students the freedom to speak from experience. To me, this was a sign that storytelling through video did have the power to open the doors for dialogue.

As a Francophone from Ontario, I was happy to have a chance to work with Franco-Manitoban students. In one particular workshop, grade eight students in a French Catholic school had made a video about the dangers of drug use and unprotected sex. Sadly, in this situation, the students and I were clearly informed that the video was inappropriate. The school wanted to organize a screening for all of its students and to invite the parents, the video would be left out since it was inappropriate for young children, and parents might not appreciate it. Although I knew it was unlikely to happen, I suggested that a separate screening could be organized for the grade seven and eight students and used as an opportunity to discuss drug use and safe sex practices. I was not surprised when the screening did not happen. The administration had no interest in exploring the use of video to spark dialogue with its students about serious issues. The much safer and cuter claymation projects I had done with the younger students were deemed appropriate uses of video. I went onto to volunteer and work with different community groups interested in

using video to tell stories. I worked with all these people to tell their stories using video or animation. I bought my own equipment and continued to learn about video production on my own and through workshops at Video Pool,¹⁴⁶ an artist-run media centre. I was very passionate about helping people to tell their stories through video, but something was missing.

I finally connected video to disability in 2004 while searching the Internet for my mother: she was looking for information related to disability supports for my brother. As I scrolled down my search results, I saw “Interdisciplinary Master's Program in Disability Studies, University of Manitoba.” I had never even heard of Disability Studies. I read through the program description and was interested in its focus on the social aspects of disability. I began to think about my studies in communication and using video to tell stories. I clicked some more and saw a section on disability art and it dawned on me that this might allow me to explore the theory related to disability, so that I could help people make videos that would destabilize accepted ideas about people labelled with an intellectual disability. This was a real eureka moment, the pieces of the puzzle seemed to fall into place. I decided to send in a letter of intention to the Program Director, in it I wrote:

I would like to widen access to media production to people with intellectual disabilities. Initiatives in video and interactive new media produced by people with intellectual disabilities will contribute to the exercise of the Right to Communicate. In addition, it will connect people with intellectual disabilities with others in similar situations around the province, the country and, one can only hope, around the world thereby reducing the sense of isolation often experienced. It will also contribute to the much needed

¹⁴⁶ Video Pool: http://videopool.typepad.com/video_pool_home.

dialogue between people with intellectual disabilities and the general public.¹⁴⁷

By September of that same year, I became a part-time graduate student, I also became pregnant. Although I often felt nauseous and tired, I loved being back in school and having the opportunity to think critically about disability. I had spent most of my life defending or explaining my brother to other people so it felt good to be around people where little or no explanation was necessary. When we were introduced to the social model of disability as developed by Mike Oliver in 1996, it gave me a new and simple way explaining that the problem stemmed from society and not from the individual. The social model turned commonly-held understandings of disability on its head and I loved it! It helped me to explain what I had felt all along: people with disabilities, like women, Native people, gay and lesbians and racialized people, are simply not considered normal according to the able-bodied white heterosexual male model and that's why they were oppressed.

However as I did my readings, I was disappointed to see that most of the research was by and about people with physical disabilities. There was very little reference to people labelled with an intellectual disability. I thought: How have I managed to be interested in a position that is marginalized even within this program? It quickly became obvious, by the absence of reference to or writings by people labelled with an intellectual disability in my course readings, that there was a hierarchy within the field of disability studies. From what I could see, people with intellectual disabilities were at the bottom of the ladder of the disability rights movement as well. As disappointing as this was to

¹⁴⁷ Boulanger, Josée, letter of intention to Deborah Stienstra, May 27, 2004.

realize, it did not stop me from trying to apply the social model of disability to intellectual disability. It was difficult conceive intellectual disability as something that is socially constructed but I knew that I had to to try. When I first began adopting a social model approach to intellectual disability, people reacted:

“But you can't say that your brother isn't disabled, he can't do many things on his own and what about people who can't speak? Do you mean to say that those people aren't disabled?”

“No, they are not, it is society that refuses to accept them as normal human beings. Sure, they differ from what many people expect but people who are labelled as having an intellectual disability are nonetheless supposed to be here and are here anyway, whether we like it or not.”

The idea that the problem was to be found in others, not in my brother, made sense to me but it didn't make it any easier to understand conceptually. I was thankful that researchers such as Dan Goodley and Mark Rapley had taken up the challenge to ensure that intellectual disability would not be left out from the development of a social theory of impairment.¹⁴⁸

As I learned about research methods in disability studies, I was relieved that one of the requirements for doing emancipatory research was to “be on the side of people with disabilities.” How could I pretend not to be? I thought to myself. Of course I was. Once my mother could no longer look after my brother, I knew that he would live with me. I wanted to learn how to make things better for him, because it would also make things

¹⁴⁸ See Dan Goodley, “‘Learning Difficulties’, the Social Model of Disability and Impairment: challenging epistemologies,” *Disability & Society* 16, no. 2 (2001) and Mark Rapley, *The Social Construction of Intellectual Disability* (Cambridge: Cambridge University Press, 2004).

better for me since I would be supporting him. I knew very little about housing options for my brother. All I knew was that he was on a fixed income receiving his monthly pension from the Ontario Disability Support Program or ODSP¹⁴⁹ as everyone calls it. Since ODSP allowed him to spend a maximum of \$445.00 on his rent and \$554.00 on basic needs, I knew he wouldn't be going anywhere on his own anytime soon. Although he might be able to rent a room in a shared apartment at that price, where would the money come from for his support? Who would cook for him, make sure he took his medication, help him with his personal care and make sure he got up on time to go to his day program? He had no money to pay someone to do all the things that my mother did for him.

Five months into my studies, Sara, one of my classmates, announced that a rally was being held at the Provincial Legislature in opposition to Manitoba's decision to invest 40 million into the Manitoba Developmental Centre (MDC). Until Sara had spoken about this, I had no idea that institutions for people labelled with an intellectual disability still existed. I had heard about institutions and insane asylums. They were places that existed in the past and that you might see in a movie. My second surprise came when she told us that People First were behind the rally. People labelled with an intellectual disability organizing a protest? I noted the date, time and place so I could go with my video camera. I would document the event and certainly find a use for the footage later. When the day of the rally finally came, I was ready. I grabbed my Sony PD 170, my headphones and my tripod and drove my now seven month pregnant self down to the Legislative Building. It

¹⁴⁹ For a Plain Language video explanation of ODSP by people who have been labelled with an intellectual disability, go to Live Work Play's Youtube.com channel to watch ODSP & Me at: <http://www.youtube.com/watch?v=lmAUWjPmkqg>.

was a freezing dry cold day, like many others in the city of Winnipeg in February. When I arrived, I saw a large crowd of labelled people, support workers, friends and other allies: it was exciting! These people were angry and they shouted, “Free our people!” and, “Shame on you!” Protesters held up signs that said: “There’s a place for people like me, it’s called my home!” “Community or a



Fig. 3. “Free Our People!” Give the Pin Back. Video still, <http://www.youtube.com/watch?v=HbuOGnl7QFk>.

nightmare.” These people were not weak, they were not victims, they were tough! I began filming right away. I was energized by their open resistance. Two men, who I would later learn represented the National Task Force on Deinstitutionalization, handed a microphone over to a short woman with a loud and confident voice: “Minister Christine Melnyk,¹⁵⁰ give us the pin back . . . NOW!” (see figure 3) she yelled as people applauded and whistled and echoed her voice. I walked among the crowd watching through my camera lens and listening through my headphones. As I zoomed in on people's faces and their signs, I noticed that many were wearing a black and yellow pin. I saw my classmate Sara and her cousin Catherine who was bundled warmly in her wheelchair, along with another woman.

Once the speeches were done, everyone was invited to enter the Legislative Building. I looked up at people slowly making their way up a very wide and long set of

¹⁵⁰ Christine Melnyk was the Minister of Family Services and Housing at the time of the announcement.

stairs. Then I noticed people using wheelchairs and their support workers heading far right away from the stairs. They must be looking for a ramp, I thought. An older woman was being helped up the stairs by a young support worker, I said to them “This is crazy, look at all these stairs! You'd think there would be a ramp near the front entrance” “Yeah, well, it's not surprising!” the support worker replied obviously unimpressed but accustomed to the lack of access. Suddenly, a tall man, who had overheard our exchanged quipped in a superior tone, “Ramps didn't exist when the Legislature was built in 1920!” I surprised myself with a quick response “Yes, but we are in 2005 now!” and the support worker ended with, “That's plenty of time to build some stairs!” He didn't slow down to respond, he continued his quick jaunt up the stairs and disappeared into the building. The woman and her support worker continued climbing the stairs at a snails's pace and so did I with my filming equipment and my extra seven months of pregnancy weight.

I squeezed into the building between as many people as I could. I didn't want to risk asking permission to bring my video camera in case they might turn me away. I remember thinking how strange it was to be entering the Manitoba Legislative Building, and being invited in for drinks and snacks, since we were opposing the Government on their decision to invest into MDC. Don't get me wrong, I was very happy to be indoors so I could warm up. My fingers and my toes had gotten so cold I worried they might break off like little icicles. Everyone gathered at the top of another set of stairs. I climbed once again and set up my video equipment. People quickly began to approach me, they had something to say. I realized that they might think I worked for a local television station so I was quick to to explain: “I don't work for a television station, I just work for myself and

I'm a student in Disability Studies. I'd be very happy if your story ended up on television but I can't say it will." I didn't want to get their hopes up of having their message broadcast on television. This didn't discourage people from wanting to be interviewed. I was relieved because I've never liked the idea of approaching strangers with a video camera, it felt too aggressive and intrusive. I much preferred people came to me because they wanted to. I was definitely in the right place: people here *wanted* to talk and I was more than happy to listen and to record what they had to say. The people approaching me were members of the People First movement. Most of them were from Winnipeg but some were from Ontario, New-Brunswick and other provinces. Some members talked about their personal experiences of life in an institution while others talked about the injustice of people incarcerated against their will. The president of People First Manitoba was wearing the black and yellow pin I had seen on others. She explained to me that the black represented the people who died in institutions and the yellow was the hope to get them out of there.



Fig. 4. "Free Our People!" Dave Weremy. Video still, <http://www.youtube.com/watch?v=HbuOGnI7QFk>

I didn't know him back then but Dave (see figure 4) was there with a young woman who I guessed was his support staff. He wanted to say something. I asked him what he thought about institutions and he responded: "It's a bad place to live in." Dave

turned over to his staff and asked her:

“Do I have to say everything?”

“No, just say what you want, you don't have to say everything.” I immediately repeated what she had just said: “No, no, no! You don't have to say anything you don't want to!”

Had I upset this person? Was his staff upset with me? This was a very difficult subject and it was all new to me. I took the footage home but wasn't too sure what to do with it. I put it aside while I finished up my classes and then gave birth to my first child in April 2005.

The following winter, I brought my son to visit my family in Ottawa. My mother had been asked by the local Association for Community Living to volunteer as advisor for the local French People First chapter. Although she was a parent and knew many of the Ottawa People First members personally, she didn't know much about People First, let alone being an advisor. My mother asked if I could read through some People First literature given to her by the previous advisor. She felt overwhelmed by all this information, and was hoping I could just give her some of the highlights. My mother gave me the pile of People First booklets, I handed her her first grandchild. I went upstairs to my old bedroom and began reading. There were books like *People First: Advice for Advisors*, *People First: Leadership Training Manual* and *A Celebration of Stories!* I tried to get a good understanding of the role of the advisor for my mother. There were no training sessions for advisors of local chapters. I tried to sum up what Bill Worrell had written in the *People First Advice for Advisors Handbook*: “As an advisor you have to be aware of the power you have in the movement because of your skills set, your life experience, your better financial situation and your social status” and “Your job is to

teach the skills you have to the members so they can have more power.” In other words “How do they [advisors] use that power to empower the members?” The book also warns about advisors having too much influence over the type of activities People First chapters undertake. Some groups miss the point and they just become recreational or social.

Basically, I told my mother, “What I understand from the readings is that the activities have to remain focused on self-advocacy and you, as the advisor, should only intervene when necessary like when the members need information, when they need help to organize a fundraiser and do some planning or maybe they need more information to make a decision, or they need support to maintain the structure and respect the People First rules.”

“I don't even know the rules myself!” she replied still looking worried.

“I'll print out some stuff for you, but essentially the members have to work towards speaking for themselves and encouraging others in the group to do the same, they have to educate the public about people who have been labelled, promote equality, there's more. OK I'll photocopy those pages for you.”

It was a lot information for my mother who, I could tell was unsure about having the necessary skills and connections needed to accomplish her role as advisor. Although she wasn't the one who was labelled, as a single mother she had faced similar barriers that People First members did: poverty, lack of education, social isolation and the resulting self-doubt. On the other hand, she was very much aware that much of this was caused by the fact that didn't seem to anywhere where Stéphane was meant to be and at the same time there hardly any support for her as parent (in other words, you wanted to keep him,

you figure it out).

According to Bill Worrell, the advisor's job is “to facilitate the process of empowerment of people who have been labelled with an intellectual disability. This process involves building relationships.¹⁵¹ This relationship must be “based on a real desire to listen to the members, respecting the members as human beings with dignity.”¹⁵² The idea that stood out the most was the importance of being a support and resource without taking control of the group. “You can't make choices for them.” The role of the advisor seemed to be a delicate balancing act between providing enough support while never abusing your power to influence the group's activities and decisions.

I continued to explain to my mother:

“Another really important thing is language. You have to say *labelled* with an intellectual disability not a person *with* an intellectual disability¹⁵³.”

“That's a lot to remember, I don't know if I can do this” she said.

Although it felt strange to say “labelled with an intellectual disability” out loud at first, I forced myself to use it since it reflected what I believed about the category of intellectually disabled. I had always been sensitive about language, maybe because my mother had never allowed name calling. When I would complain about a kid taunting me at school, my uncle would tell me that “sticks and stones will break your bones but names will never hurt you,” but I never really believed him. I knew that words had power. They

¹⁵¹ Bill Worrell, *People First: Advice for Advisors* (Downsview: National People First Project, 1988): 41.

¹⁵² Ibid.

¹⁵³ In French it would be “une personne étiquetée d'une déficience intellectuelle” and not “une personne avec une déficience intellectuelle”. The use of the word “déficience” or deficiency, in French sends a clear message that something is wrong or something is missing with this person. It is very common to hear people say “une personne déficiente” (a deficient person) for short or worse “les déficients” (the deficient). It had grated on my ears for a long time and so I welcomed this People First practice of introducing the word “label” to express resistance to dehumanizing language.

could hurt just as much as kick in the butt with the advantage of leaving no visible marks. I ask people to close their eyes and imagine “a mongoloid child,” “a newborn with a congenital abnormality,” “a man who suffers from retardation,” “a mentally deficient woman,” or “a mentally challenged boy.” These words immediately give the impression that these categories actually exist and create a binary between who is considered normal and who is considered abnormal just like white and black, man and woman. It was exciting to read the People First literature and it suddenly dawned on me that I should contact the Winnipeg chapter to see if members would like to make videos in support of self-advocacy.

Pre-Development: Getting to Know People First Members

When I returned to Winnipeg after Christmas, I found the contact information for the local People First 's chapter through People First of Canada (PFC). Their office happened to be located two blocks away from where I lived. I got the advisor's contact information and asked her if I could come as a guest to one of the chapter's meetings. She said she would have to ask the group. Two months later I was invited to a meeting. The chapter met once a month in a common room of an apartment building, where quite a few members lived. There were about thirteen people at the meeting that day. I recognized some of the people I had interviewed at last year's rally. I saw Dave and Valerie, and a few others seemed familiar. I'm not sure why but it had never occurred to me that they might be here. Once all of the People First business was done, Valerie who was the president, invited me to speak. I presented myself as a graduate student in Disability

Studies at the University of Manitoba and as a community filmmaker. I told them about my brother being a People First member and my mother being an advisor in Ottawa. It was important for me to say this since I certainly didn't want to be perceived as a “professional outsider,” assuming they had a similar mistrust of professionals. I asked if anyone might be interested in telling stories with video, and I explained that I might be able to use the work as part of my thesis, if the university approved it and they agreed to it. Most of the members were interested and wanted to get started. I wasn't quite ready myself, so I suggested that they take some time to think about the sort of things they would like to talk about in their videos. And I could come back, so we could discuss it.

As I finished my presentation and asked people if they had any questions for me, a newsletter entitled *Institution Watch* was being distributed. I looked down at my copy and read Volume 1, Number 1. How could this be the first publication for such a newsletter? After seeing everyone in action at the rally, I assumed that this type of publication would be old news. It was shocking to realize that *Institution Watch* had just been created. I asked members if they could tell me about more about this newsletter. That's when I learned that Manitoba still had not just one, but two institutions for people who have been labelled with an intellectual disability. One was MDC and the other was St. Amant. The provinces of Alberta and Saskatchewan also refused to close down their institutions. Valerie explained that one of People First's priorities was to get provincial governments to shut down institutions. People in the room were upset that nobody was listening to People First about this, as they knew what it was like to live in those places. I listened and took all of this information in. Then Valerie suggested, “Maybe we could make a longer video



Fig. 5. “Free Our People!” Rally. Video still, <http://www.youtube.com/watch?v=HbuOGn17QFk>.

about closing institutions.” I couldn't believe it! This was my first meeting with the group and here we were already talking about making a documentary about a very serious problem: People First

members were true activists! “I don't know if you guys remember me but I was at the rally last year, the protest against investing in MDC, I had my video camera and I interviewed you,” I said addressing Valerie and then “I interviewed you too,” to Dave. “I didn't even think of bringing the video with me, but I'll get something ready for next time if you would like.”

Of course, they all wanted to see the video of the rally. (see figure 5) I honestly felt as though the stars had aligned to allow me to use my skills in video production to help people who had been labelled. The following month, at the next Winnipeg People First meeting, they saw the first video that would spark the work for the next two years. I had named it *Free our people!* since that's what everybody had been shouting at the rally. After seeing the footage of the rally and what People First members had to say in the interviews, they invited me to present this video at the upcoming Manitoba People First Annual General Meeting (AGM).

Over a month later, I showed the video at the People First of Manitoba AGM. There were about between 45 and 55 people representing local chapters from throughout the province. There was no video projector, just a television set so I connected my laptop to the TV and held the microphone that was connected to the public address system up to its speakers so that everyone could hear. It seemed to work because I could feel the energy in the room changing. I looked at people's facial expressions as they watched the video and I could see that they were very upset. This made me feel a bit nervous. What was I getting myself into? This was a very serious issue, and up until my first meeting with Winnipeg People First, I had no idea that it even *was* an issue! Dave from the local Winnipeg chapter was there and said: "We *have* to make a video!" Another member who I had never met before was trembling with rage, "It's not fair to leave people in there, we have to get them out!" she said. Although I knew little, I felt the same way, my heart was with them and I knew something had to be done. In the last few months since my last meeting with the local People First chapter, I had had time to think about Valerie's idea of making a longer video. I knew that the National Film Board of Canada (NFB) had a long history of making socially critical documentaries and I knew about their history of putting media in the hands of the people through programs like *Challenge for Change*. So I thought I should contact the NFB for support if Manitoba People First decided to go ahead with making a video.

I explained this to the audience of People First members and said that if they decided that they wanted me to call the NFB then I would. The Manitoba People First Executive Committee met and decided that they would like to go ahead with making a

video about closing institutions. They had some funds to devote to projects that promoted inclusion, some of them could be used to make this video. I spoke with Dave at this event and asked him if I could meet with him to learn about institutions.

For me, things really got started once I met with David at a restaurant after the Manitoba People First AGM. It was the first time I spoke with someone about life inside an institution. I sat down in front of him with my note book and tried to write as much as I could as he spoke. Sometimes I sketched things out. I learned that David's parents had passed away but that he had brothers and sisters who he kept in touch with.

Dave said:

I was 14 years old when I went there. There were 31 boys in one room. Boys slept with boys. Nobody cares about nothing there. If you tell a worker something happened to me last night, they don't do anything. It was a bad place to live. There's nothing there, that's what I think about that place. I ran away nine times. I came to Winnipeg, I hitchhiked. One time the worker was sleeping in a chair so I took his keys to get out of the building. That guy got fired.

Why didn't anybody know about this and do something about it? How could I be meeting with someone in 2006 to talk about making a video that would let people know what really happened inside institutions? The more I listened to Dave's stories, the more I was convinced that people had to know about institutions. Then a scary thought entered my mind: What if people don't believe these stories? Dave was patient with me as I took notes. I had to ask him to repeat himself many times since I wasn't used to the way he spoke. Dave looked at me and said: "We are little people. What do we have to do for people to listen to us?"

"We'll make a video and hope more people will listen," I respond. There was no turning

back for me after that meeting.

I was not interested in telling stories that were objective. I didn't want survivors' stories competing alongside stories by staff from the institution, doctors and politicians. These people already had opportunities and access to resources allowing them to share their perspective and publicize their views about intellectual disability and institutionalization. In my mind, I would make a video with People First that might create a balance in this fight for “the truth” about institutions. I knew that because of their social position, survivor stories might not weigh as much as the seemingly scientifically-based justifications used by politicians, medical professionals and parents in favour of institutions. The former might be perceived as “just stories” by people who had been discredited as incompetent, whereas the latter would be perceived as rational and more objective descriptions by credible, competent and educated people. I was very aware that the playing field was unequal, but I thought that it would be a step in the right direction to add more survivors' stories. When would enough people start believing them? I really didn't know, but I thought the more stories people tell about living in an institution, the more people on the outside will begin to believe them.

These ideas gave me the courage to contact the NFB for support to make the video. The producer for the Winnipeg NFB studio at the time, had never heard of the Manitoba Developmental Centre. He invited me in for a meeting and I brought the *Free our people* short video along with me. I explained that I wanted People First members to be involved in making the video. I told him how the idea of the video came from the members, and I still wasn't sure what working with members to make the video would

look like. During our first meeting, I was happy to learn that he had a sister with a disability. A personal connection at least told me that he had some idea about what and who I was talking about. He explained that the first step was to start working on a proposal that we could submit to the NFB programming committee. He gave some suggestions and handed me a few examples from previously funded NFB documentaries.

I went home and worked on organizing the notes and research I had done so far into a structure that began to resemble a documentary film proposal. That was when I discovered *Inclusive Research Methods People with Learning Disabilities*. The principles outlined by Jan Walmsley and Kelley Johnson were very helpful to me and I included these slightly reworded in the proposal to the NFB:

- The research problem must one that is owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities.
- It should be collaborative – people with learning disabilities should be involved in the process of doing the research.
- People with learning disabilities should be able to exert some control over process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.¹⁵⁴

I had also learned about ethical guidelines developed by the First Nations Information Governance Committee through one of my classes in ethnographic research. By substituting “Aboriginal peoples” with “people with disabilities,” I was able to think of my role as a non-disabled person and my relationship with the film as I engaged in a process which would produce knowledge about people who have been labelled with an

¹⁵⁴ . Jan Walmsley and Kelley Johnson, *Inclusive research with people with learning disabilities past, present, and futures* (London: Jessica Kingsley Publishers, 2003), 64.

intellectual disability. Disability groups shared the sentiment of having been “researched to death” for the benefit of others outside the community. The *Principles of Ownership, Control, Access, and Possession (OCAP)*,¹⁵⁵ and the abuses of power that led to their necessary development, further confirmed my belief in the need for People First Manitoba members to own and to control the content and final representation of their stories.

In late May, I got a telephone call from the National Coordinator of People First of Canada (PFC). PFC happened to have federal level funding to make a video about institutions. The National Coordinator had learned about me from the Manitoba People First advisor who was the same advisor for the local chapter. The National Coordinator wanted to meet with me to discuss working for PFC on a video project that would involve, not just Manitoba, but also the provinces of Saskatchewan and Alberta. First, I had to discuss it with People First Manitoba members since I had already started up a process with them.

During this meeting, I explained that my experience was mostly based in participatory approaches. I had taught video and animation to community groups and school aged children so they could tell stories and express themselves through those mediums. The staff at the national office were surprised and perhaps a bit skeptical about my proposal to make the process inclusive. However, as I explained that it would be an advantage to make the film inclusively to show that People First doesn't just talk about inclusion, it practices it. And besides, I could not make this video any other way, this was

¹⁵⁵ Schnarch, Brian, *Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities*. For the First Nations Centre and National Aboriginal Health Organization, (2004): 2.

People First and from what I had read, they were all about speaking up for themselves and building inclusive society. On their end, the staff would be forwarding my CV to the Executive Committee of the Board of Directors as well as the proposal as it stood presently. They would decide if they wanted to commit to working with me to make their video. After my first meeting with the National Coordinator and the community development agent, I couldn't help but wonder why there were no labelled people working at the national office.

The members of the board of Manitoba People First met to talk about my meeting with People First of Canada and the possibility of including Saskatchewan and Alberta. They agreed to move in this direction since now more stories would be heard and there would be funding from the national office to make the video. I was happy to receive an email near the end of April confirming that, indeed, they were on board to experiment with a participatory approach to making the video.

Just a month after my meeting with PFC, I met again with the producer at the Film Board to get some feedback about the proposal I had sent him. He had the chance to discuss the project with his co-workers and they wanted to know what I thought about the idea of members directing the film with my guidance. Instead of an inclusive approach, it was becoming collaborative. I still wasn't sure exactly what this would look like. I had never directed a longer documentary myself, and I knew that I needed guidance. Being in regular contact with the producer at the NFB was very helpful.

I continued to meet with Dave and Valerie in person and over the telephone. Both of them were committed to the video project from the very beginning. I depended on

Dave's knowledge of institutions and Valerie's experience with living under the Public Trustee and in a large group home. They were my first guides in terms of a People First perspective as I continued to adjust the proposal to include them as co-directors.

It was now July and my classmate Sara had another invitation. This time it was celebration: it was her cousin Catherine's birthday and interdependent living party. Although Catherine had multiple disabilities and required supports for daily living, she was celebrating 20 years of living in her own place. I asked Catherine and her support network of staff and family for their permission to bring filming equipment and make a first attempt of working together to make video. Dave, Valerie and Kevin Johnson would be working with me. Kevin was a very outspoken People First member I had noticed at the monthly People First meeting. We were given permission and on the day of Catherine's celebration, I went to pick up Valerie, then Kevin and finally, Dave at his apartment building. That's when I met Mark Blanchette, a People First of Winnipeg member and good friend and neighbour of Dave's. He helped Dave into my van, asked us what we were up to, said he had nothing to do so he would come with us for the day. So, we were now four People First members and me making our first public appearance as a team.

While Kevin and Valerie asked Catherine's mother questions and Dave mostly listened in, Mark and I were behind the camera. Mark was holding the boom pole for the microphone while I kept the camera steady. While we interviewed Nicola Schaefer, the room was full of friends, family and community living allies. I was amazed to see Catherine living in her own place surrounded by so many friends, staff and family. Her

house was owned by the Prairie Housing Coop while her support services were provided by an agency called L'Avenir meaning the future in French. To me, this was the way people should be living and I thought that my brother Stéphane could live this way too! There was hope for him to live on his own with support. He wanted his own place and a job. Now I saw that it was possible, people were successfully living with supports. After Catherine's party, Valerie, Dave, Kevin, and I decided to meet at Dave's to look at the footage we had shot to talk about what we liked and didn't like and what to do next. Valerie quickly became the group's memory: She always remembered and reminded us to follow up on our do-to lists. Although I took notes during meetings, many ideas would have been lost along the way if it wasn't for her amazing ability to remember!

My First Visit to the Manitoba Developmental Centre (MDC).

In August of that same summer, Dave invited me to come along with him and his support worker Christine to visit a friend who still lived at MDC. Christine had been taking Dave to MDC once a month for about a year now. Dave wanted to interview his friend about living at MDC and he wanted to ask him if he'd like to move to Winnipeg. I was excited about going to MDC, I wanted to see for myself what it was like. I also wanted to know if Dave could video-interview his friend. We (the co-directors including myself) wanted to interview someone who still lived inside an institution but we first had to find out how to get permission. Christine drove with Dave next to her and I sat in the back with my video camera.

After about an hour of driving, we get to the small town of Portage la Prairie,

Manitoba. Dave tells Chris: "There, that's where you turn." We arrive at the institution. It looks like a giant old hospital with many buildings. We take a left and Chris points to an abandoned building and explains that Dave used to live there. I lower the window and film the building from the car. We keep driving a little ways and Chris tells me that we are at Evergreen Cottage where Dave's friend lives. It certainly doesn't look like any cottage I've ever seen. It just looks like a smaller version of the other hospital-like buildings on the grounds. I leave my video camera in the car. We walk up to the cottage, but the door is locked. We ring the bell and as we do a staff walks out with a resident. She asks us who we are looking for. Dave says he has come to visit his friend. His friend is already sitting outside with a few other residents. He looks tiny next to his younger but much bigger lifelong friend Dave. Dave introduces me to him and I sit down with them. Dave explains that we're working on making a video about institutions. Dave asks his friend if he wants to be in the video. "Would it be OK if we asked you some questions about living here at MDC and things you remember when Dave was here?" I add.

"Oh sure, I'd like that" answers Dave's friend in a soft and gentle voice.

There is a young woman who appears to be working or volunteering here but she looks too young to have any kind of authority around this place so I ask her: "Who should I talk to to know how to get permission to interview him?" She suggests that I should talk to the supervisor and that his office is in the basement of the "cottage". He opens the door for Christine and I and as we walk in I notice large metal bars in the stairwell, this place looks more like a jail than a cottage I think to myself. Locked doors separate the stairs from a hallway and from the kitchen. We walk down the stairs to the supervisor's

office. I feel a bit awkward as I enter his office. I am pretending to be ok with this place so I can get information. I try to be polite and to the point. I ask him what I must do to get permission to interview Dave's old "dorm mate". He gives me the telephone number to MDC's CEO and says that I must contact her. I thank him. Christine talks with the supervisor about his work here and as I look around his office for clues that would confirm some of the stories Dave has been telling me, I overhear the supervisor saying that he's been here for 25 years and that his father used to work here too. Looks like this an "histoire de famille" for them too, I think ironically.

As we leave the supervisor's office, Christine points to a room just between the stairs and the office, it's a lock up room, a side room, a time out room or a quiet room. Whichever word you use, it is basically solitary confinement for people labelled with an intellectual disability. I've seen pictures and read stories about these rooms in books like *Hear My Voice: Stories Told by Albertans with Developmental Disabilities Who Were Once Institutionalized*¹⁵⁶ and *Speakeasy: People with Mental Handicaps Talk About Their Lives in Institutions and in the Community*¹⁵⁷ and images from Burton Blatt's works such as *Christmas in Purgatory*¹⁵⁸ and now I am walking past one. I wish I could ask questions about this room to the supervisor but it might compromise our chances to interview Dave's friend so I don't. I don't stop to peek through the door, I don't want to get caught snooping around. We walk back up the stairs and leave the cottage. While I am outside

¹⁵⁶ Alberta Association for Community Living, *Hear My Voice: Stories Told by Albertans with Developmental Disabilities Who Were Once Institutionalized* (Saskatoon: Copestone Writing and Illustrating, 2006).

¹⁵⁷ Karin Melberg Schwier, *Speakeasy: People with Mental Handicaps Talk About Their Lives in Institutions and in the Community* (Austin: Pro-ed, Inc., 1990).

¹⁵⁸ To view these images, go to The Syracuse University Archives site at <http://archives.syr.edu/collections/faculty/blatt/christmas.html>.

with Christine and Dave, I notice that there are a few more residents, some are having a smoke, others just chatting. They turn to look at us and smile. One man begins to talk to Dave, Christine and I but he can't finish his sentence because he is quickly escorted away. The young staff is assuming that he's bothering us: "Let's go drink some juice inside" she says as she slips her arm under his. "Oh, we were just talking about the nice weather!" I tell her but she has already escorted him back into the "cottage." I hear some noise just behind us: it's the supervisor unlocking the door to step outside the cottage. He approaches me and takes the little piece of paper she had given me in her office away from me. He looks a bit irritated: "I just spoke with the CEO and she said that you have to contact the Public Trustee" he says handing me another piece of paper.

As Christine drives Dave and I away from the so-called Evergreen cottage, we pass by the abandoned building where Dave had lived for many years. I ask Dave if we can stop here for a bit so I can take some images with my video camera. Dave walks out of the car and sits down on the steps leading to two doors. I walk between the building walls looking up through my lens. How many boys lived and suffered here I think to myself as I zoom into a window with broken glass and remember stories Dave has told me. "What should they do with this building Dave?" I ask him. "Blow it up, blow it up."

The next day, Christine calls me to tell me that the CEO called her and boy was she mad! I become worried about the possible consequences for Christine. Can she get in trouble for this? Then, Chris won't want to be associated with this video project anymore if it's causing her problems with her job. This is my first experience in an openly confrontational situation and it is quite stressful. So many thoughts rush through my

mind. Will I be in trouble with People First of Canada? Will Chris be in trouble? Will Dave get scared and want to back out? I panic for a little while as I imagine all the possible reactions and consequences. Then, my fear turns to anger as I realize the power this institution has exerted over me and the fear it succeeded in putting in me, if only momentarily. These are bullies, the grown up kind and they have the law to back them up! Oh, I am angry now. I summon up my courage and call the CEO, I am not going to hide. I get an answering machine so I leave her a message: "Call me if you have any concerns about the video project we're working on."

My next call is to the Public Trustee's office. As I talk to Dave's friend's appointed trustee, I feel as though I am being grilled by a cop investigating a crime.

"So you were filming a building that's been shut down?" she asked.

"Yes I was. It's the building where David lived for 18 years and he is not under the Public Trustee. I don't think that has anything to do with the Public Trustee's office, does it? I am simply calling you because I was given your name as the person I must contact to obtain permission to interview Mr. G. I never tried to film him without permission nor any other residents. I was under the impression the last time I called the Public Trustee's office that substitute decision making is usually done in regards to acquiring property, moving or travelling, decisions about spending large amounts of money. The person I spoke with left me with the impression that the person who is considered vulnerable could still decide to speak for themselves." I am really worked up by this time

"Well, you understand that he can't make that decision, the Public Trustee will. We have to make sure that the right decision is made for the vulnerable person, a decision that is in

the best interest of that person. There are different things we need to consider” Now I am losing really my patience so I ask:

“Have you ever met Mr. G? Has the Public Trustee ever met him? It must difficult to make a decision in the best interest of a person you don’t know.” I say sarcastically and the conversation went on like that. I was unbelievably thankful for my freedom after that telephone call. How many times would I have landed in that side room with a dose of lorazepam or some other p.r.n. (staff lingo I've picked up for 'meds as needed') had I been labelled as a child and sent to a place like MDC?

I was still fuming when just a few days later I received an official looking letter. The Public Trustee's Office had made a decision informing me that they did not consent to Dave's friend's participation in the video. What? I hadn't even sent in a description of the project with examples of questions we might ask Dave's friend. I brought the letter to the next co-directors group meeting. I was upset about the refusal but also about the power the Public Trustee had over people's lives. What could I or the co-directors do about this? Would it be like this for all the people still living inside institutions? Parents had had to give their child up to the province as a condition of admission to the institution. I couldn't help but think of how well this fortress was protected! We still had time to think about this problem and try to contact survivors and People First advisors in other provinces, so we let this issue simmer for a while. We knew there were many people who had gotten out, however we still didn't have that many contacts.

Christine was the first support worker that I had ever met. I knew some of the

people who took my brother out of the house to give my mother a break, but growing up, I saw them more as adult babysitters and friends of the family than as support workers. So until meeting Christine through Dave, the work of support workers had remained a mystery to me. My mental image resembled more the type of worker that I had seen at the institution: controlling and condescending. As I observed the way Christine and Dave interacted, I was shocked at how respectful Christine was with Dave. She spoke to him in a normal voice, there was no hint of superiority or belittling. She treated him as an equal! How did she know to behave like this? Where had she learned this? I concluded that she must have a family member who was labelled with an intellectual disability so I asked her:

“Christine, how did you become a support worker?”

“I did some respite for my neighbour's son while I was still a teenager and I thought, this is a job? I had always enjoyed helping people so I signed myself up to the developmental services worker program offered by Cambrian College in Sudbury.”

“So, you don't have a family member labelled with an intellectual disability?”

“No, I don't.”

Getting to know Christine and seeing her support Dave in doing what he wanted gave me hope. There were good support workers out there! She was the living proof. I had seen Catherine, Sara's cousin, living in her own place with supports and now Christine was changing my way of seeing support workers. I wished that my brother could have support workers like her if he ever got the chance to live in his own place. I was learning about so many things that I knew were important and I also knew that we wouldn't be able to fit

everything in the video. I kept notes hoping we would have time to make more videos with People First members once we were done.

Working on the Film Proposal at Dave's.

Dave's apartment became our home base for developing the proposal. If MDC staff could see him now: Who would have ever thought that Dave would be involved in making a very critical film about MDC? Each weekend, we met for about four hours. None of us missed these meetings. I felt really lucky to have found people willing to work this way. I also felt that Valerie, Dave, Kevin, Mark and I were all as equally invested and motivated to work on this project. I would bring Tim Horton's donuts and Mark would prepare a pot of coffee for all of us. Although we knew that PFC would fund the production of the documentary, I hadn't signed a contract yet and was still not given a deadline. It was exciting to have all the time we needed and the freedom to imagine whatever we wanted. The possibility of receiving extra funding from the NFB also motivated us to work hard on the proposal. I knew that the process would be very long, and I explained to the co-directors that this would be a longterm engagement. They were committed.

At first, I liked the idea of using Dave's story as the focus of the film. We could then interview other survivors and they would be secondary characters in the film. However, since we had agreed to work with People First of Canada, I knew that the film had to focus equally on the three Prairie provinces. The film would have to focus, at the very least, on a survivor from each province. As we discussed the best way to tell these stories, Kevin spoke up: "I think the film should have lots of people in it. I don't think it

would be right to focus on just one person, like Dave's story. People First is a movement, there are lots of members in People First so I think we should show as many peoples' stories as possible.”

Valerie agreed: “It would be more powerful that way.”

It was important to show that people labelled with an intellectual disability were not isolated victims, powerless and voiceless. By including many survivors, the film would also show that there was a supportive community. This made a lot of sense because it would give more power to the stories, they would stand next to each other increasing their credibility through the commonality of the experiences. Dave's story could not be perceived as an isolated case of abuse.

As we discussed these things, I was usually sitting on Dave's couch with my laptop on his coffee table. I typed as fast as I could while sometimes also scribbling things down in my journal. I then took the notes home and combined them with other information I had learned about institutions and the People First movement. I tried to respect the ideas and the spirit of the conversations as much as I could, but changes would occur. For that reason, I would read the proposal out loud the following week so that the co-directors could give me their feedback, corrections and additions. That's how we developed the proposal together, going back and forth like this for months until it was ready to hand in to the NFB.

During one of these weekly meetings, Valerie was excited to tell us about a trip she'd made to the Provincial Archives. She had found archival photographs of the Manitoba Developmental Centre dating from the 1960s (see figure 6). The following

week I went to the archives and took pictures of these pictures, printed them out and brought them to Dave's. I asked them what they thought about using the pictures to start a conversation. Valerie, Kevin and David sat at his kitchen table with the copies of the

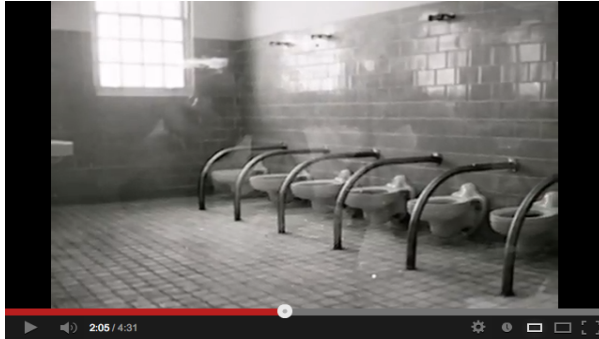


Fig. 6. "Images of the Manitoba School for Mental Defectives. Video Still, <http://www.youtube.com/watch?v=VB4hLGFpQ9w>.

pictures. Using pictures to spark a conversation worked really well and the exercise was worthwhile. We ended up using these archival pictures in the final cut of the documentary. I also used them to make a short video.

One thing I remember repeating quite

a bit during the meetings was the fact that this was their film as People First members and as survivors: "You guys are the experts here, you are the one who have been fighting to shut down institutions. This will be a People First film so it should feel like a People First film and the only way to make happen is by having you guys take the lead." For me, the co-directors were my guides to remaining faithful to a People First perspective to the film and my gurus about the realities of living with the label of intellectual disability. I really wanted the co-directors' and the movement's energy and emotion I had witnessed during the rally at the Manitoba Legislature to shine through the video.

As I continued to meet periodically with the producer at the NFB to give him updates on the proposal and discuss different approaches to co-directing the documentary, he suggested that I look into digital storytelling.¹⁵⁹ This was an accessible method of

¹⁵⁹ The links that I had for *Life Stories*, *Tales from Bridgeview* and *Our World* produced in collaboration with the NFB are no longer online. For other examples of digital storytelling, visit The Center for Digital Storytelling's Youtube channel: <http://www.youtube.com/user/CenterOfTheStory>.

introducing the five People First members to making a personal video. I followed some of the links the producer had sent me to watch examples and did a bit of research of my own. I saw that people used photographs from their family albums or personal collections, sometimes they used archival material, objects, art and took new pictures to tell autobiographical stories. Digital storytelling was based on the assumption that “everyone has a story to tell.” It invited so-called ordinary people (as opposed to famous people) to tell personal stories primarily using pictures and a voice-over narrative. Most of these stories were only a few minutes long. I thought it might be a good exercise for us as an easy way to get into making videos. We could decide once we were done if we wanted to incorporate parts of these stories into the final documentary. I prepared a workshop outline to guide Kevin, Valerie, Mark and Dave in the process of making their own digital story. In the proposal to the NFB, there would be a “second phase” of digital storytelling workshops to allow other People First members to share their stories as well. These digital stories would go onto a website that would be created for the film and these videos.

Making Contacts During the Closing Institutions, Opening Communities Conference

In late September, the co-directors and I were invited by PFC to the Closing Institutions, Opening Communities Conference co-organized with Community Living Manitoba. We were very excited to present the work we had done so far, to get members' feedback and to tell people (see figure 7) about our plan to submit a proposal to the National Film Board. I explained that Valerie, Kevin, Dave, Mark were working with me

to write up this proposal so that the entire process of making the film would be inclusive, I wouldn't be working on it alone. I would facilitate the making of the film working



Fig. 7. “Valerie Wolbert”. Closing Institutions, Opening Communities Conference. Video still, <http://www.youtube.com/watch?v=5dss1BCaZPM>.

alongside People First members as a co-director.

Dave and I also mentioned what had happened with our request to interview his friend at MDC, Valerie shared her story about getting herself off of the Public Trustee. Kevin asked if

anybody had ideas or comments they wanted to share with us. One man got up to speak: “I don't think it's a good idea to interview people who live in the institutions. It could be dangerous for them. What if the staff get mad at them. They could get mad at them.”

Until that point, I had not thought about that risk nor had Kevin, Valerie Dave or Mark. I couldn't help but think that this was our first public presentation of the project and we were already doing something wrong! A few other members in the room agreed with that man and thought we should stay away from people who were still stuck on the inside. Our questions could get them in trouble. We answered a few other questions but I kept thinking to myself: How could the film tell the story of institutions without current experiences? How would people believe that institutions were still an unacceptable housing option if they thought that they were so much better now? First it was the Public Trustee, now the barriers were coming from within. Then I had a strange thought, could

the Public Trustee be concerned with Dave's friend's safety? Is that why they refused our request to interview him? But then I thought, that doesn't make any sense, if the Public Trustee's office was truly concerned about his safety, they would be pushing to move him out of MDC not stopping a self-advocacy group from interviewing him.

During the conference, we met and interviewed Bill Hogarth, a People First Saskatchewan member who survived 42 years at Valley View Centre in Moose Jaw. He told us how many times he had run away from there, hoping to gain his freedom. One time, Bill said that he jumped a train trying to get away from Valley View. As he grabbed onto the train, he had a seizure. He woke up to find that his legs had been severed. Kevin asked him if he regretted it and without hesitation Bill answered:

“I don't regret running away from that place for one minute. I even ran away from that place in my wheelchair.” We asked him if he wanted to be in the film and if we could interview him at home. Bill immediately accepted and we were happy to have found another survivor. I asked Bill for his contact information and told him I would be calling him soon.



Fig. 8. “Wayne Beever's Story”. Video still, http://www.youtube.com/watch?v=AeMd_nQ2icQ.

It was shortly after meeting Bill that a new staff person from PFC informed me that a family wanted to share their story. Three women, Valerie, Elaine and Marilynne (see figure 8.) had been trying to find justice for their brother and uncle

for years. One of his nieces had taken the time to write everything down in great detail. They explained how Wayne had been falsely accused of a sexual assault and put into a locked ward for eleven years. How could their brother and uncle Wayne find justice?

It was in these types of situations I felt really useless: they had told their story so many times and none of the harm done to Wayne had been so much as acknowledged. Facing these family members reminded me of my mother's own frustration of telling her story over and over again and for what? She had managed to get little extras here and there through the respite system but nothing had changed. I wished there was more I could do for these women and for Wayne. However, I had to accept that this was the approach I had chosen. I would record their story and try to get it to reach new eyes and ears.¹⁶⁰

We received three more names of survivors, thanks to local agencies supporting people who lived in the community. I remember thinking that aside from a few roadblocks, how well the process of finding survivors was going. I met the first survivor who I will name Leonard, in his new group home. This was the first time I stepped foot into a group home. The staff was very welcoming and helpful. Since Leonard didn't use words to communicate, I depended on the staff to tell me what she knew about his story. She was very proud to talk about the positive changes she had seen in him since he had moved out of MDC in less than a year. I filmed Leonard and then plugged my video camera into the television set to show him what I was doing with the camera. Since I didn't know him, I couldn't tell if he understood that he was being filmed. In this situation, I felt there were no risks for Leonard since the point of the interview was to show the

¹⁶⁰ To watch the interview done that day, go to: http://www.youtube.com/watch?v=AeMd_nQ2icQ.

positive changes that had occurred to him since moving out of MDC. Staff were proud to be a part of that change. I felt comfortable with that, and so did the staff. A few months after the interview, I received a call from the Leonard's support agency. They hadn't realized that he was still under the Public Trustee at the time of the interview. I sent in a request and soon got a letter from that office explaining that no, the interview could not be used. I was starting to find this Public Trustee quite annoying. In some situations like with Catherine Schaefer who lived in her own apartment as well as survivors who were labelled with profound intellectual disabilities, obtaining consent wasn't complicated since family members were very supportive of People First as a movement. They were also knowledgeable and actively involved in creating alternatives¹⁶¹ to institutionalization. The second contact I received through a local agency was with a man named Gerald. I gave Dave a call to see if he might remember him:

“Do you know a guy by the name of Gerald Hoffmann? He was at MDC for over 40 years.”

“No, I don't know that guy.”

“I just talked to his father and he said I can meet with them next week on Thursday afternoon. They might want to be in the documentary.”

“That's good.”

“I'll let you know how it goes.”

“Ok. Yup.”

“I'll talk to you later Dave, have a good day”

¹⁶¹ Nicola Schaefer, *Does She Know She's there?* (Markham: Fitzhenry & Whiteside, 1999).

“Yeah you too Hozay, don't work too hard!”

The following week, I pick up Mr. Hoffmann and we drive across town to visit his son. He now lives in a group home with three other men. When we get there, a young woman opens the door and lets us in. She's the support staff working today. She must be no more than 22 years old. I haven't visited many group homes and I don't really know what support workers actually do. I'm always surprised by how young the women are, well, most are women. I feel like an imposter as I walk into the group home, but it helps that I am with Gerald's father even though I've just met him. I make sure to stay close to Mr. Hoffmann and to behave as his guest. The support worker is friendly. She has prepared coffee for us and my presence doesn't appear to bother her. We first head into the living room but it's very dark and just won't do for a video interview so I have to ask: “Would you mind if we sat in the kitchen? It's bright in there, I think it would look much nicer on video.” “That's fine, Gerald likes to sit here to drink his coffee.” Gerald makes his way over to the kitchen and reaches out to the coffee machine. “Gerald, no, sit down. I'll bring the coffee over,” The young staff says to Gerald. I don't like the power this young woman has over Gerald. He doesn't look too pleased. I'm not too pleased either but I figure this is not the time to start advocating for him to get his own coffee, so I bite my tongue. His father echoes the staff words: “Gerald, sit down. They are very good to you here, aren't they?” Gerald looks at his father, then at his staff, he sits down at the table still not looking too pleased. “Gerald is a good boy,” Mr. Hoffmann says to me in his defense. I feel Gerald's frustration. Why can't he serve himself coffee?

Once the interview is done, I spend some time filming Gerald as he smokes his

cigarette on the front steps of his group home. He looks straight into the camera and smiles. He smokes his cigarette very slowly, enjoying each movement. He brings the cigarette to his lips, gently inhaling and exhaling the smoke. As I look through my camera lens, I see a proud man with an intense look in his eyes. He has endured so much and he has kept his dignity despite what life has thrown at him. There are quiet moments like this one that I enjoy so much. Gerald shows no signs of feeling self-conscious in front of the camera. He is totally relaxed and doesn't care that I am there filming him. Not everyone is capable of allowing me to film like this. When I'm done, I show him what I have filmed. He just smiles and continues to smoke his cigarette with the same enjoyment and intensity.

I review the material at home and take some notes for our next interview. Gerald remembered his experiences with exceptional clarity, he was still obviously very upset about the things that happened to him while he was there. Unlike Dave who had left MDC in 1975, Gerald had been there up until just a few years ago. I feel very lucky to have met Gerald and look forward to sharing the content of the interview with the co-directors on the weekend. I know Dave will be able to do a great interview with Gerald, next time we'll go together. Next time never happens: I get a telephone call from the agency that shared his contact with me:

“Gerald's father doesn't want you to use the interview or to call him anymore” my heart starts thumping, what did I do? How did I manage to blow this? “Mr Hoffmann is afraid of how his family might feel if they found out about Gerald's time in the institution. They don't know much about it and he's worried about how it might affect them. You know, he's

very old and this has brought up all kinds of bad memories and he doesn't want to talk about it anymore.”

I felt bad for Mr. Hoffmann, he was very old and it must be horrible to realize that your child lived in a prison for disabled people where he was neglected and abused. But to be honest, I was even more disappointed to lose the opportunity to interview Gerald along with Dave for the documentary. I could tell he had more things to say. He obviously wanted to share his experiences, he was angry about what had happened to him in the institution. But, his father didn't want me contacting them again. What should I do? Maybe I could contact Gerald directly at the group home and interview him on his own. I knew he would talk to Dave and I. But then I would cause grief for this old man who visibly cared for his son. He may be the only family member who visited him since his mother passed away.

After discussing it with the co-directors, I realized that I had no choice. I couldn't contact Gerald. Not that the decision was easy and clear cut. The discussion went back and forth trying to weigh the risks for the family and Gerald against the benefits for him and the film. If the co-directors and I went ahead and contacted him, would we be responsible for damaging relationships between a father and other family members? What about the agency that had trusted us and put us in contact with his father? Since the film was now being presented as a PFC project, we couldn't risk damaging that relationship either. Even if we had met Gerald on his own, the support workers or Gerald himself would likely have told his father about this video interview and the result would have been the same. This was a new barrier that I hadn't anticipated. A part of me felt back then

(and still feels this way) that it was unfair to silence Gerald. He had been so willing to speak out about his experiences. This was his life. *He* was the one who had endured over 40 years of institutionalization, not his father or his siblings. His siblings didn't play a very important role in his life, I try to justify to myself, why should I care about them? They probably don't even visit Gerald I thought to myself. Maybe Gerald's father was afraid that his other children would judge him harshly for having left Gerald in such an awful place. I imagined that if I was Gerald's sister, I would be pretty upset:

“Why didn't Gerald stay at home with us, Dad?”

“The doctors told me it would be the best place for him, he would get the best medical care. Your mother and I didn't know what to do with him, it was hard.”

“Yes, but didn't you *know* what was going on in there? Didn't you visit?”

“Yes, we visited him but we didn't even know there were other places where Gerald could live, we thought this was the only place so he had to stay there.”

“You and mom should have taken him out of there!”

“We couldn't anymore, Gerald was under the Public Trustee, they made the decisions not us. We had to give him up when we brought him to the School, that was the way it was back then.”

I thought of my own grandmother and how difficult it was for her when bad memories came to the surface . . . what could we do but let go of Gerald? So we continued our search for survivors. In late October, the co-directors and I weighed the concerns shared by members from other provinces against our desire to interview a person still living on the inside. We came up with a compromise. We would only ask

Dave's friend very general questions about his life in the institution. I sat at my laptop ready to type. "So what kinds of questions do you think might be safer to ask him?" I asked Kevin, Mark, Valerie and Dave.

"How long have you lived at the Evergreen cottage?"

"What are your favourite foods?"

"Do you have any hobbies?"

"Who are your best friends?"

"Do you have brothers and sisters?"

"What is the one thing you like doing the best?"

"Do you have roommates? How do you guys get along?"

"Do you remember living with Dave at Northgrove?"

"Do you like dogs, cats or other animals?"

I typed the questions. Dave also really wanted to ask his friend if he would like to live in Winnipeg, but we were afraid to put that down on the list we would send to the Public Trustee, so we left it out. We talked about the risks for Dave's friend and felt comfortable that if we stuck to questions that were general, we wouldn't be putting him in a difficult position. Was it the right decision to make in light of the concerns raised during the Closing Institutions, Opening Communities Conference? I wasn't sure. We stuck with it and made our second attempt. The day after I emailed our request along with the questions, I received an answer. The Public Trustee's office was quick to respond. This time they informed us that Dave's friend could participate in an interview for our video project but that we had to stick to the questions I had attached to the request. If we wanted

to ask him any other questions, we would have to get their approval first. I was very surprised by this turn of events. Why did the Public Trustee' office have a change of heart? Organizing a trip to MDC when we could all go wasn't possible before Christmas so we decided to wait. There would be plenty of time to meet up with Dave's friend after the holidays and besides our proposal to the NFB had to be handed in soon.

As I tried to learn more about life on the inside, I continued to read first hand stories and to watch videos from the PFC video library like *Keys of Our Own*, *Candle of Hope* and *Pat Worth and The Name Change*. I looked through the NFB's archives and found films about institutions like *Eternal Children*¹⁶² and *Danny and Nicky*. I also consulted *Christmas in Purgatory* and *The Family Papers*¹⁶³ by Burton Blatt. As I read story after story and looked at the pictures in Blatt's books, I felt sick, I got migraines. Seeing small children, men and women young and old so neglected, it was horrifying. I couldn't help but think of what might have happened to my brother had he been left in the hospital. These family¹⁶⁴ and from survivors like Bill Hogarth and Harold Barnes.¹⁶⁵ I imagined how Dave must have felt when he first went to the institution at the age of 14. It broke my heart. I was disgusted and angry. I remembered a People First member saying that: "Some people don't believe our stories!" How could people not believe them? There was so much documentation about the realities of life inside institutions. It was obvious to me that people were telling the truth about their experiences. How could they make that stuff

¹⁶² I recently found a teaching guide accompanying the film at the time of its release: <http://www3.nfb.ca/sg/98063.pdf>. About the children depicted in the film, the guide asks: "are they to be a complete loss to their families and to society?"

¹⁶³ Burton Blatt, Ozolins, A., and McNally, J., *The Family Papers: A return to Purgatory* (New York: Longman, Inc., 1979).

¹⁶⁴ To listen to their story, go to: http://www.youtube.com/watch?v=AeMd_nQ2icQ.

¹⁶⁵ To listen to Harold speak, go to: <http://www.youtube.com/watch?v=iWRuzzy8HeA>.

up? Whenever I spoke to people about the film project, many would ask me “But where else will they live?” They said people would end up on the streets as it had happened to some people during the big push for deinstitutionalization in the 1970s and 1980s. People First members knew about this and they were concerned about having the proper supports in place before people got out. The image of people previously institutionalized now living on the streets made a strong impression on the public. So when I talked to friends and acquaintances about the film, some continued to say, “It's better that that people with intellectual disabilities at least have a roof over their heads,” while others thought, “Things have changed and it's so much better now.” “Why is it necessary to make a film about closing institutions?”

I knew everything wasn't the way it should be. I was starting to visit group homes and I wouldn't want my brother to live in one. Just because many things still had to change for people living in the community, didn't justify keeping silent about people's experiences of institutions, much less leaving people in there. As I continued to work on the proposal, I saw that the names of institutions had changed from being homes for incurables and for the mentally defective to developmental centres and long term care facilities and other euphemisms. When they first opened their doors, the people who were admitted to institutions were called inmates and patients, now they were called residents. After long telephone conversations with survivors in Saskatchewan and Alberta, I learned about all kinds of strange systems of reward and punishment, like the start system, cigarettes and meal tickets. They told me about the people who tried to run away and were punished when they got caught. They talked about people who committed suicide,

friends who were murdered through violence or neglect. Others told me stories about the residents who had their babies taken away and given up for adoption. I read about people who were forcibly sterilized so they could never have children. There were too many stories like these that made it difficult for me to provide the rational answers that skeptics wanted to hear. Thankfully, Community Living Manitoba had responded in a very rational manner to the Provincial Government's announcement to invest 40 million dollars into MDC. They had filed a human rights complaint against the Province of Manitoba and the Public Trustee based on their denial of community living and continued institutionalization of the people still living at MDC and had written an alternative proposal for the use of that money. They demonstrated the availability of supports by existing agencies for the 325 adults¹⁶⁶ still living at MDC.

Valerie, Dave, Mark, Kevin and I continued to meet each week. I had started bringing documentaries, animated and short films about disability or by people with disabilities. This gave us a chance to talk about the way people with disabilities were represented in the films. It also gave us some concrete examples to refer to, and to think about what we liked and what we didn't like. We watched many of the short films from the *Disabling Imagery?* by the British Film Institute¹⁶⁷ teaching guide for disability and the moving image.

During another one of our meetings, I showed up with my usual box of donuts from Tim Horton's and a documentary entitled, *How's Your News?*¹⁶⁸ a road movie with five people who were labelled travelling across the United States and asking random

¹⁶⁶ Association for Community Living-Manitoba, *Proposal regarding the Manitoba Developmental Centre* (Revised February 21, 2009): 1.

¹⁶⁷ *Disabling Imagery?*, The British Film Institute, 2003, DVD.

¹⁶⁸ *How's Your News?*, Director: Arthur Bradford, 1999, DVD.

people on the streets “*How's Your News?*” I loved watching people's reactions to the five reporters. It was the power of disability to reveal people that I enjoyed so much. We weren't trying to make a funny film like this one, but the freedom associated with a road trip idea and the “in your face style” were certainly appealing. I was curious to see what the co-directors would think about it.

After talking about certain scenes in the film and a few criticisms, Valerie and Kevin wondered if we could travel as a group like they did in *How's Your News?* Although I didn't want to give false hopes that we could actually pull this off, I was thrilled to see that we were thinking along the same lines. We really had nothing to lose at this point, and if we did manage to get enough money to travel as a group, what an experience that would be! From that day on, the concept for the documentary took a whole new direction. The co-directors would not only be involved behind the scenes developing the documentary, they would become part of the story. We knew that travelling together to interview survivors would cost a lot more money but it was worth trying: everyone wanted to come along. Now that there was a possibility of travelling together, Valerie wondered if another woman could join the group: “I don't want to be the only woman.” I realized quite by surprise that I didn't count as another woman. I had been so enthralled by the work that I had come to think of myself as simply one of the gang. I realized how silly that was since I had not shared their experiences, even as a sister. I was not labelled and had not experienced the consequences of being labelled as a person with an intellectual disability. I had had all the opportunities a non-labelled, white woman living in the city could have. That's how I got to work with them in the first place. I

remained “the filmmaker,” I was a facilitator. It was at this point that Susie Wieszmann, the secretary of People First of Winnipeg joined the group of co-directors.

Now that we wanted to travel together, we had to come up with a reason. That was how the idea of The Freedom Tour was born. I don't think any of us realized it at the time, but we were now not only preparing to make a documentary but we now had to organize a public awareness tour of sorts! Was I naïve or just overly confident? Possibly, a combination of both, propelled by the determination of a missionary. I loved to dream big and I encouraged the co-directors to do the same. The other side of that was the enormous responsibility I felt for realizing those big dreams. I often had doubts and was afraid to fail. I hadn't gone to film school, I hadn't directed a feature length documentary before. What if I was guiding the group of co-directors in the totally wrong way? What if we couldn't pull this off? Am I really listening to the co-directors or am manipulating them to do what I want to do? I would go back and forth between total confidence and self-doubt. My moments of self-doubt always happened when I was working alone at my computer. During one of my lonely moments of writing, I stumbled upon this on the Internet: “And everything happens in the process of making art. . . Everything you do kicks open a door, and if you just go through that door, you find yourself somewhere you hadn't anticipated.”¹⁶⁹

Once I was back at Dave's apartment and had a chance to review everything with Susie, Kevin, Valerie, Mark and Dave, I felt my confidence coming back. We were on the right track. I just had to trust that by working collaboratively, by listening and putting

¹⁶⁹ Chuck Close. “Forget Inspiration – Just Trust the Process,” *doug toft*. (September 19, 2011) <http://dougtoft.net/2011/09/19/forget-inspiration%E2%80%94just-trust-the-process>.

myself in their shoes to understand their point of view, we would come up with a film that would be true to survivors' experiences and People First's work to close down institutions. That was the joy of working collaboratively. It seemed to make anything possible! We took the People First motto “We can do it!” literally and handed in our film proposal to the NFB hoping for the best.

Development: Making Personal Video Stories and Planning *The Freedom Tour*

The NFB agreed to fund the development phase of what we were still calling the Free Our People project. That meant that I had money to deliver the digital storytelling workshops, to create a website where they could be uploaded, and to develop a film treatment or a detailed document about the film we were proposing based the Freedom Tour idea. The NFB's involvement in the documentary film project gave it an aura of credibility. I was very aware that the NFB brand was a sign of quality to many people. I knew that People First could really benefit from being associated with that idea.

I had asked the producer if the co-directors could be paid for their involvement, because, thanks to them, we would be learning about something new about making videos with people who have been labelled with an intellectual disability. The producer had made room in the budget to pay each of the five co-directors \$1000.00 for the time they would devote to developing their video stories. I was so proud about this. Little did I realize that it would soon turn into a nightmare for myself and for the co-directors. It never occurred to me how complicated it would be to pay them! It turned into a project of its own once I realized that their monthly income was going to be affected by the cheques

they would receive from the NFB. In the midst of working on these videos, I became involved in a battle with social workers as I tried to find a way to pay the co-directors for their contribution to the writing process without penalizing them. Essentially, the Manitoban government was subtracting the money they received from the federal NBF agency. There really is no way to win! Talking to the social workers handling the co-directors files was like talking to machines, they simply repeated whichever policy they had to respect without any ounce of common sense and human compassion. This was a one time payment, it could have been a gift but no, they ended up having their subsequent monthly pay cheques reduced as result of this.

For people on a fixed income, a \$1000.00 cheque for doing creative work is a big deal, but there was no way to get through the bureaucracy. There was no one willing to listen and to allow the co-directors to keep this money. I felt my heart racing and my head pounding each time I spoke to the case workers. I don't think I could sustain having to talk to people like that on a long term basis. It's not surprising that caregivers who deal with the social services system burnout. Just in a few months of trying to find a solution for this problem, I saw how quickly the system could suck my energy and make me feel powerless. Institutionalized poverty. Dead ends when doors open. Lack of control. Not being able to enjoy an unexpected amount of money for doing something that you are passionate and knowledgeable about. I could do nothing about it and that made my blood boil. While trying to recognize their work by paying the co-directors, I had actually made things harder for them. It was difficult not to get side-tracked by situations like these. Lack of financial resources was one of the biggest problems for people labelled with an

intellectual disability but I couldn't put everything aside and start fighting this battle, as badly as I wanted to. The co-directors and I still had so much work to do.

From Digital Storytelling to Video Self-Portraits

The six of us, along with Christine and other people who volunteered to help once in a while, began meeting at the NFB studio in downtown Winnipeg. This was quite far from Dave's so transportation had to be organized. I asked Christine, Dave's support worker and People First Winnipeg's advisor, to provide transportation. We had money in the workshop budget to pay her for the extra driving. We had the NFB studio pretty much to ourselves during the weekend. Christine always stayed with us during the workshops. She had become an integral part of the project. It was nice to have access to the screening room (see figure 8.) where we could surf the Internet and I could show the co-directors how video editing worked and what could be achieved with such software. I wanted them to get a better understanding of the overall process of making a documentary. I remember that during the first digital storytelling workshop, I was quite excited to be at the Film Board. Our small group had moved from Dave's apartment into the studio of the NFB Winnipeg Studio (see figure 9). Not bad for a group of people who started off at a People First meeting with just an idea!



Fig. 9. “Why make Free Our People Project?” Video still, <http://www.youtube.com/watch?v=wChQ5MciU48>.

After watching a few digital story examples, Kevin said, “I don't really like the pictures. I want to use video that way people can really see us and hear us talking.” The others weren't too impressed by the examples either. Now that we were watching them together, I understood what they meant. It felt distant. We could hear peoples' voices but could not see them as they spoke. Some digital stories felt a bit too poetic and more abstract. The co-directors wanted to represent themselves in a more direct or realist style. Nonetheless, everyone had brought personal photo albums to this first workshop and each person took the time to show their pictures. (Although digital storytelling approaches made use of pictures, the idea of bringing photographs or entire albums to the workshop was equally inspired by my brother. He loves looking at photographs and sharing photographs with others. It's a great way to talk about family, about his experiences, his friends and so on.) It was helpful to see everyone's pictures since we could all learn a bit more about each other beyond the advocacy work. Although this exercise was useful, it became clear that the co-directors were unlikely to use any of them in their videos. Dave wanted to do his video about MDC, Valerie wanted to focus on her experience of living in a group home and getting herself off of the Public Trustee, Susie wasn't too sure but she thought she might like to

sing and Mark wanted to do stand up comedy. So there we were in the screening room having decided that a digital storytelling approach just wouldn't do.

This discussion helped me to realize that using pictures as the material for video storytelling could be difficult for people labelled with an intellectual disability who have lived in institutions, group homes and different foster homes: They just didn't have that many pictures. People may have had pictures of themselves before they went in and after they got out but there could be a 10 or a 40 year period where people had no pictures of themselves or the people they had lived with. To create an autobiographical video, a digital story or a personal video was tricky. Friends and family members could help fill some of the gaps but sometimes finding these people also became difficult. Sometimes staff knew the people they supported quite well and could help with the person's story. It also dawned on me that in this respect, I had failed miserably in my collaborative approach. How had I managed to come this far with digital storytelling? I had assumed that since it was an accessible way to tell personal stories that it would somehow work. Had I shown the co-directors examples before the workshop, I would have known that they were not interested in this approach. In the end, it wasn't a problem, since I just adjusted the workshop and the co-directors simply did what they wanted to do anyway. That was the whole point, wasn't it?

Coming back to the issue of pictures, it wasn't that no pictures existed of people who had lived in institutions it was just that they had been put in photo albums without names or dates. Dave, Valerie, Kevin, Mark and I discovered this during a visit to MDC. We had learned that MDC had an archive so we made an appointment to visit. We had

also wanted to meet with the CEO but we were told that she wasn't available. During this visit, Dave spent some time with his friend while the rest of us we were taken on a tour. We first stopped in a room with an old dentist's chair and bookcases. I looked on the shelves and saw old titles like *The Abnormal Mind*, *Measurement of Adult Intelligence*, and *Control of Human Behavior* by Ulrich. We then went to a room filled with photo albums. As I flipped through the pages of what seemed like mountains of albums, I thought I might be able to find pictures of Dave's friend but I realized that there was no way of identifying the people who lived out their entire lives there and died there. I was so depressed after visiting the archives. How could someone ever hope to find photographs of a family member who had lived at MDC? There were so many albums and so many faces of people, all anonymous. I wondered what would happen to these pictures when the institution would shut down. It reminded me of the many pictures I had seen of Native children in residential schools at the Manitoba Provincial Archives. I, a complete stranger, had access to these photographs yet, most had never been seen by the people themselves or their families.

We had from the end of January to mid-March to develop, film and edit the co-directors' personal videos. I had attended workshops led by and worked with video artist Erika MacPherson in the past and admired her work and her ability to help people tell stories using video. I was very excited when she accepted to work with us to create the personal video stories. Working with Erika was invaluable. Over and above doing camera work and editing, she gave us many useful suggestions and encouraged the work we were doing. The approach to making the personal videos was very much like the one we had

adopted to write the film project proposal. The co-directors spoke, Christine, a friend, and myself took notes. Based on the notes, we would sit together and discuss the ideas with the entire group. Everyone shared their ideas about each person's story. Then, we made a storyboard for each video to help us imagine a storyline. I did not encourage the co-directors to write a script for their videos. I knew they felt more comfortable telling their story rather than reading it from a piece of paper. Once we thought we had identified the main points of their story, we turned statements into questions. For example, I could ask Valerie, "What can you tell us about being under the Public Trustee?" so that she could begin sharing her experience. I would then have a list of all the points she wanted to talk about and would question her on these to make sure she covered everything she had planned to say.

Dave used a different approach to make his video. He simply told me he wanted to meet with his siblings because he had some things he wanted to talk about. In this situation, Erika captured more in *cinéma vérité* style the conversation that took place between Dave, his sister, and his brother and his wife¹⁷⁰ in a small kitchen (see figure 10). Erika and I intervened a few times with questions but Dave led most of the discussion.

About mid-way through the personal videos workshop, we still hadn't interviewed Dave's friend. Since we planned to travel to Portage la Prairie to interview Patricia Endall, an MDC survivor,¹⁷¹ we thought this would also be a good time to finally interview Dave's friend living at the Evergreen cottage. I called MDC to know when and where we could meet with him but I was informed by a senior administrator that the Public Trustee

¹⁷⁰ To watch Dave's video, go to: <http://www.youtube.com/watch?v=tVIPg8xZSOW>.

¹⁷¹ To watch the interview with Patricia, go to: <http://www.youtube.com/watch?v=yKKUWCIqW4Y>.

had contacted the CEO to stop the interview. MDC would not allow us to interview him anywhere or at anytime. We had waited too long to do the interview and had missed our opportunity. I knew that at this point, there was no sense in trying again. Enough information about the film we were working had circulated within the intellectual disability community to know that it would not be very flattering for MDC. I know there was a part of me that did worry about putting Dave's friend in an awkward situation even though the co-directors and I intended to ask very general questions about his life at MDC. None of us made any other attempts of trying to interview him after that.

The personal videos done by Dave, Valerie, Kevin, Mark and Susie were edited at



Fig. 10. “David Weremy”. Video still, <http://www.youtube.com/watch?v=tVIPg8xZSOw>.

Video Pool, an artist-run media production centre in downtown Winnipeg. Just as I had organized transportation to the NFB studio, I did the same for the editing sessions at Video Pool. I could do this since the producer and I had put money aside for transportation.

Sometimes Christine was available to give rides, other times the co-directors took a taxi. Using taxis wasn't always straightforward though. For some reason I can't quite remember, the taxi drivers didn't want to take the co-directors home. I gave the driver each person's address and the order in which he should drop them off, along with my cell phone number. For some reason, this was a problem. One taxi driver refused to take them

and we had to call up another company. None of the co-directors were eligible for Handi-Transit at the time and anyway, that service was so unreliable, it would not have made sense to depend on it. Unreliable transportation, enforced reliance on public assistance (making it impossible to financially recognize their contribution to the project) and public trustees added themselves to list of structural obstacles faced during my collaboration with the co-directors.

Working with Erika in the Video Pool editing room gave us a really good sense of how we would work to edit the documentary. We all sat with her to watch the rough cuts she had put together and everyone could pitch in with their reactions and suggestions. It was a back and forth process between the co-directors, myself and Erika. We were very proud of the five videos that resulted from this process. There was a Provincial Election coming up in May, and the NFB producer encouraged us to use the videos as an opportunity to engage with the candidates. The co-directors and I thought that this would be a good opportunity to practice presenting the videos and speaking publicly before heading on the tour. We called it the Free Our People Video Screening and distributed flyers to everyone we knew. With the help of PFC and Christine, I made up a list of agencies providing supports in Winnipeg. PFC's administrative assistant sent it out to its local contacts, Christine personally handed out invitations to all the group homes she visited and staff she came into contact with. I put posters everywhere I could think of, so did Valerie and Kevin.

For this event, I asked the co-directors if they could think of public venues that we could access for free or at very little cost, that was wheelchair accessible, had a surface

on which to screen videos, had a public address system and access to the Internet. A location such as this wasn't so easy to find. We finally found a downtown community theatre that cost us only \$50.00 to rent. It had everything on our wish list, except for one problem, the only spots allocated for wheelchair users were at the rear of the cinema. This was not acceptable, we wanted wheelchair users to feel welcomed not crammed to the back of the theatre! I asked the volunteer responsible for the theatre if we could temporarily remove three rows of seating near the front of the cinema. She said no.

The day of the screening, we were expecting around one hundred people. A mutual friend rallied some of their friends and a few ratchet sets to help us. Within 45 minutes, all three rows had been removed and neatly tucked behind the stage curtains! I remember how exciting it was to see that big open space right in the middle front of the cinema. When people started coming in, we could proudly escort them to the new wheelchair accessible area we had created! Peter Bourne's¹⁷² interpretation of *We Shall Overcome* was playing. Valerie was the host alongside the PFC national coordinator, Kevin was responsible for asking the candidates the questions, Susie introduced each of the five videos, and Valerie showed everyone our planned itinerary for the Freedom Tour. Dave shared a bit of his experience at MDC and asked the candidates one of his own questions and Chris sat next to him to interpret since we wanted to be sure that everyone would understand what he had to say about MDC. Each political candidate had 5 minutes to respond to the questions and Valerie ended by thanking everyone and saying “We hope that by telling our stories, it will give others the courage to do the same so that institutions

¹⁷² To watch Peter Bourne's video interview about his experiences at Woodland's School in BC, go to: <http://www.youtube.com/watch?v=rRCrdMM4VQ>.

and abuse of the rights and freedoms of people with disabilities will become a thing of the past.” The evening was a success and we hoped the same for the Freedom Tour. Of course, then we had to put all three rows of seats back!

As the date for the Freedom Tour drew closer, we continued to refine our proposal and build a structure for the tour. Inspired by the idea of a vox populi, I asked the co-directors what they thought of setting up a sort of booth where people could drop in and share their feelings, opinions and stories about institutions. We brainstormed and came up with the name Video Booth. Valerie and Kevin suggested we use the black and yellow

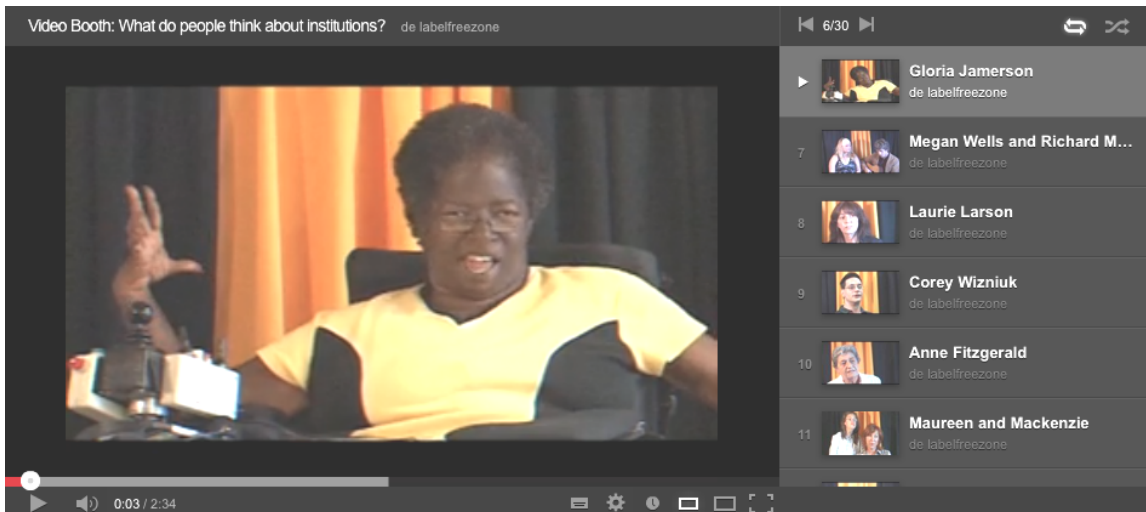


Fig. 11. “Gloria Jamerson”. Video still, <http://www.youtube.com/watch?v=f3Bs5EoVrPQ&list=PL0F7E7DBDD074AB63>.

deinstitutionalization colours as a backdrop (see figure 11) so I bought three panels to mimic the pin. Most of the Video Booths took place in the board rooms of Community Living offices. Video Booths were set up in Winnipeg, Regina, Saskatoon, Edmonton and Calgary. People First members would work alongside the camera person either independently or with me to collect video booth testimonies. We would ask each person to end their story by saying: “Free our people!” Over 30 video booth clips were

recorded.¹⁷³

Collaboration of support workers was essential for all the events we organized, since we depended on them to pass on the information to the people living in the group homes or to people they supported living in their own places. If the people they supported were interested and needed accessible transportation, we hoped that staff would make the reservations or drive people down to the events. Essentially, staff had to want to support people to attend or participate in these events. I was aware of how easy it would be to simply post our flyer on the group home bulletin board and leave it there.

In some cases, the need for support went further. For example, one of the participants at the Winnipeg Video Booth, relied on his staff to input his statement into his communication device. In this situation, I saw how critical the role of support worker was. She had to be willing to type his words, as he wanted to express them, into his speech device. Had he not received this support, he could not have shared his thoughts on MDC. I was very thankful that his staff was supportive and willing to take the time to listen to him and to input his statement so his voice could be heard.

It was absolutely necessary to include people who did not speak to communicate in the documentary to illustrate a saying from the disability movement, “Just because I don't talk, doesn't mean I have nothing to say.” Many of these people would have been housed in the cottages for so-called low-grades¹⁷⁴. As one mother describes where her son lived, “He was in the lowest of the lowest cottages...they didn't even have a TV in there. They

¹⁷³ Some of the video booths can be viewed at youtube.com/labelfreezone while others can be viewed at <http://www.youtube.com/freeourpeople>.

¹⁷⁴ “Low grade” was a term used to describe people who were considered to be the less competent or the most “profoundly disabled” as opposed to a “high grade” who would be considered as having a “mild developmental disability”. It was a continuation of the grading of people such as idiot, imbecile and moron or severely retarded, moderately retarded and mildly retarded.

just milled around all day with nothing to do.” I wanted to make sure that the co-directors and I wouldn't only be interviewing people who could speak very clearly. I noticed that there was this assumption when I first started asking advisors if they knew any survivors we could interview. Many of them thought that they should only recommend people who could express themselves verbally since they would be in a video. I insisted that people who communicated mostly with gestures and body language stories could and should be told because they might have had a different experience of institutionalization since it was assumed that they could *not* tell their story. Although this was true in a sense, family members were able to share quite a bit of information, enough to piece together a story. In situation, Judy, as Mark explains in narration of the documentary, had to go upstairs to avoid hearing about The Michener Centre since it would make her sick for days. Since Judy couldn't speak nor could she listen to the words Michener Centre, it was her sister Bonnie who told her story just as she had done as a “trusted voice” in the book *Hear My Voice*.¹⁷⁵

As the tour quickly approached, I contacted survivors by telephone to confirm interview date and times and to answer any questions they might have. I also sent them a list of the questions we might ask them during the interview. In one case, I called Anita to touch base with her and to make sure everything was still a go for the interview. Whenever I called, someone else usually answered the phone, I assumed it was a staff person. As I waited for Anita to pick up the receiver, I wondered what her staff thought about me and about this film project or did they even know about it? I hadn't explained

¹⁷⁵ Alberta Association for Community Living. *Hear My Voice: Stories Told by Albertans with Developmental Disabilities Who Were Once Institutionalized*. Saskatoon: Copestone Writing and Illustrating, 2006, 37.

anything to them and didn't really know if I should or had to. For me, just the act of calling people in their group home about this film project felt like a subversive act. We had no trouble communicating over the phone so I thought why should I talk to the staff? Weren't they there just to provide support? We exchanged practical information. "There will probably be three of us, the camera person, a People First member. Right now I'm not sure which member it will be but I will be there too." She gave me her address and the nearest intersection. I felt that her permission was enough for me and that it should be for staff too. I felt I would be behaving paternalistically by going over Anita's head and asking a "higher authority" permission to interview her in what was supposed to be her own home. I didn't want to question Anita's ability to decide whether or not she wanted to be interviewed in her own home about something she had experienced. I was tired of trying to get permission from public trustees, parents, staff and agencies.

Let me share a conversation I had with a group home staff person about protecting the privacy of people "with intellectual disabilities."

"We have to protect their right to privacy" explains the staff at a residence.

"Protect their privacy? There is different staff here almost everyday and nobody has chosen to live here or with whom they wanted to live. That's not much privacy." The staff person looks exasperated but I continue, "Let's say Jane is unhappy about the way a staff is treating her and she gets her brother to help her make a telephone call to the local media and they show up at the door. I bet that journalist would have a tough time trying to interview her!" I say defiantly.

"That journalist wouldn't even make it through the door!" the staff says proudly.

The staff is right, the journalist *wouldn't* make it through the door. No one can enter the group homes without authorization from the agency providing the supports, who usually also owns the house¹⁷⁶.

"You know the right to access the media can be taken really far," concludes the staff.

I assume that he meant that the residents could abuse their access to media to damage the image of the agency. His attitude that protecting the agency over the rights of a resident is not only taken-for-granted but it is considered legitimate. Although many large institutions have been closed across Canada, working collaboratively to make experience-based videos with people who have been labelled will not necessarily be easier since many community-based systems of support are based on the same segregational and pathology-based premises as large institutions. In other words, people now live outside institutions but continue to be congregated, to attend sheltered workshops and specialized day programs. "They [are] transported as a group in private vehicles to and from these sites."¹⁷⁷ which means that their daily lives are "mainly composed of others with developmental disabilities and staff, both not necessarily of their own choosing"¹⁷⁸This traditional model of community services continues to segregate while creating what the authors call the illusion of inclusion¹⁷⁹. Closing the institutions is one thing, changing the assumptions upon which they were created is another.

Aside from preparing for interviews, the co-directors and I organized activities to

¹⁷⁶ There are exceptions. To read more about the importance separating support services from housing, read Nicola Schaefer's *Does she know she's there?*

¹⁷⁷ Deborah S. Metzel and Pamela M. Walker, "The Illusion of Inclusion: Geographies of the Lives of People with Developmental Disabilities in the United States," *Disability Studies Quarterly* 21, no. 4 (Fall 2001): 120.

¹⁷⁸ Ibid.

¹⁷⁹ Ibid.

get other People First members across Canada involved in the tour. A T-shirt design (see figure 12) contest inviting people who have been labelled to participate was one of these activities. PFC and Community Living Associations helped to spread the word about the contest and over fifty entries from across the country were mailed to us. Mark, Kevin, Valerie, Dave, Susie and I met at Perkins Restaurant



and Bakery to choose a winner for the contest. The winner was from

Fig. 12. Valerie Wearing the Free Our People T-shirt, <http://www.flickr.com/photos/freedomchoiceequality/1243318649/in/set-72157601491568127>.

Newfoundland and he wrote a short poem as part of his painting. It read: “In the black of the earth, in the dark of the clay, lies a seed who is sleeping and dreaming of day.”¹⁸⁰

Music for the documentary also came from the labelled community. We could use *We Shall Overcome* interpreted by a Peter Bourne, a People First member and survivor from British Columbia. Kevin asked Winnipeg band The Fabulous Scott-Tones if they could write some songs for the documentary, which they did: *We Gotta Close the Institutions* and *See It All in the Video*. Ken Harps, who was the advisor for People First Rankin Inlet, Nunavut, and his son gave us the song *Free the people*.¹⁸¹

There was no need to hire musicians, the People First community had all the talent that was needed. It would be impossible for the co-directors and I to organize all the

¹⁸⁰ “A People First member from Newfoundland reads the poem written by Dougie Dunne’s friend Stephen,” <http://freeourpeople.tumblr.com/page/2>.

¹⁸¹ To listen to the song “Free the people”, go to: http://www.youtube.com/watch?v=up8G_ScY5Nk.

events that would take place during the Freedom Tour, so we asked for help. A local group called Friends of People First organized the send-off event and each Prairie chapter was asked to organize and host an event during the tour. Manitoba People First would organize a Walk and Roll for Freedom in Portage la Prairie, Saskatchewan People First would organize a vigil at the old Valley View cemetery and Alberta Society of People First would organize a picnic for survivors and tour members. Despite the enormity of the project, things were falling into place. People First of Canada had its funds to support the tour and they planned to send some of their national representatives and a staff member on the tour along with us. With the support of the NFB, there would be enough money in the budget to have two RVs with their respective drivers, an experienced director of photography (to compensate for my lack of experience of directing a feature length documentary), a sound technician and a technical coordinator. The co-directors and I would organize and facilitate video screenings and discussions of the five personal videos, as well as setting up Video Booths in cities along the way to collect as many testimonies as possible. The NFB would help publicize these two events through the usual promotional channels.

Production or Getting the Stories on Tape

On June 27th, I got the news that the NFB wouldn't be supporting the Tour in the way I had expected. The producer explained that we would have to make some changes to the scope and nature of the project in order to be successful with the programming committee in Montreal. Essentially, the Winnipeg NFB studio preferred to support a web-

based video project instead a documentary film. I immediately understood that this meant a seriously reduced budget for the tour. Drastic cuts would have to be made to our wish list! I have to admit that I felt devastated by this news. I needed a few hours to collect myself before I could talk to anyone about it. I had to calm down and think about how the tour could still work with less than half the resources. *How not if.* People First members and Community Living associations from across Canada knew about the upcoming tour. The T-shirt contest, Video Booth invitations, and word of mouth had reached many people. Susie, Kevin and Mark had planned their summer holidays around this and there was no way that I could even suggest to Dave and Valerie that we might not be able to pull it off. There was no doubt in my mind that the tour had to go on. Postponing it wasn't an option either, there was a risk that it might never happen.

I breathed in and out deeply. I told myself to look at the bright side. If the co-directors, PFC and I agreed to modify the proposal, the NFB would still provide us with a camera person, video and sound equipment, an extra car and my per diems. We were stuck in a difficult position and we decided that I would quickly rework the proposal to secure some support by the NFB for the Tour. Although a modest website had always part of the proposal as a place to publish the video stories that could not fit into the documentary, we had not thought of it as a separate entity. Despite the last-minute stress this was causing, there was an advantage to this change of focus. The documentary film would now become a People First of Canada production: no compromises would have to be made in terms of the tone of the documentary. People First members would have ultimate control of and responsibility for the film. Less than a month before the Tour, I

learned that the Montreal programming committee had approved the revised version. In the budget there was money for a camera operator, his equipment rental and a car. As for the rest, I cut wherever I could in expenses and People First of Canada filled in some of the void.

The Freedom Tour Hits the Road

We hit the road as planned on August 18th. On the trip there were the five co-directors, Christine, an assistant in charge of video blogging, the camera operator, a People First of Canada staff as well as five People First of Canada members who were interested in joining us on our two week tour across the Prairies. Our strained budget forced us to stay in some pretty terrible motels. Christine became both the RV driver and support person invited by Kevin who arrived a few days into the tour. This was nothing like the more predictable Annual General Meetings taking place in a Holiday Inn or a Delta Hotel. We were definitely roughing it by those standards.

The co-directors, as well as other members on the tour volunteered to interview survivors they already knew from their involvement in the self-advocacy movement. The experience of travelling across the prairies as a group was certainly an important motivation for organizing the Freedom Tour, but equally as important was the fact that interviews would always be done by one of the co-directors and myself. This was one way of reducing the power imbalance existing between me and survivors. By leaving this choice up to the co-directors and the PFC members, it was our attempt to “*to reduce, as much as possible, the symbolic violence [harm] exerted through that [interview]*”

*relationship.*¹⁸² Ideally, these choices would have been done much ahead of time but in reality they were done as people expressed a desire to interview such and such a person. Survivors, and self-advocates, as people who had been labelled, were in a better position for putting interviewees at ease and establishing a climate of trust than I was as a non-labelled filmmaker. I felt much more comfortable meeting survivors with People First members. In some cases, the co-directors and PFC members were able to ask survivors very direct questions about their lives in the institution.¹⁸³ This effect was especially apparent in Dave's interview with his friend Wayne Beaver.¹⁸⁴

I kept the list of questions Dave, Valerie, Kevin, Mark, Susie and I had developed during the winter on my lap, and took notes while survivors talked about their experience with one of the co-directors or PFC members. I sometimes interjected with these questions, sometimes with some of my own. Once it seemed as though they were done talking, I took over with the questions and new ones I had jotted down. I had noticed during previous interviews that long pauses between questions gave people the chance to think, to remember, to prepare their story. Sometimes the pause was so long that I began to think, "Maybe he hasn't understood the question or has nothing to say." I found that if we were patient enough and kept our mouths shut, we realized that the person *had* understood, they just needed time to reflect. This was when the assumption of competence became very important. I had to assume that the person was taking the time they needed to respond or to decide not to respond. This was something the co-directors

¹⁸² Pierre Bourdieu et al., *The Weight of the World: Social Suffering in Contemporary Society* (Stanford: Stanford University Press, 1993), 609. Italics original.

¹⁸³ Bourdieu talks about this effect of the interviewer who is socially close and familiar to the interviewee: the risk of objectifying the interviewee is diminished since it would result in the interviewer's own objectification, see page 611.

¹⁸⁴ *The Freedom Tour* 2008, DVD.

and I had practiced and talked about quite a bit during the months leading up to the tour.

Giving people plenty of time by going beyond that point of discomfort found in silence was a sign of respect. “Wait” I would whisper or sign with my hands to the co-interviewer or tell myself as we risked silencing the survivor by moving on to the next question too quickly. In addition to allowing for very long pauses, we always asked people if had anything else they wanted to say. Was there a question we forgot to ask? Was there something else they wanted people to know? This approach did make for quite lengthy interviews, but it was the least we could do in return for intruding¹⁸⁵ on them by asking them to remember and to talk about things I was sure they would rather not. By interviewing survivors this way, I hoped that we were sending a message that survivors' stories would not be subjected to doubt and to scrutiny. We were not there to question them about the veracity of their stories, we were there to bear witness to their experiences of institutionalization.

The people present during the interview were important, it made a difference. Some of the survivors were alone, in their own home when we interviewed them. I found the atmosphere of those interviews to be more relaxed. I didn't feel like we were unwelcome guests. The person could invite us into their apartment without having to negotiate or owe any explanations to staff or family members. Interviewing people who lived in group homes was a different experience.

Valerie, the camera operator and I showed up at Anita's group home for her interview. Anita walked outside to greet us. As we had done with all the other interviews,

¹⁸⁵ Bourdieu qualifies all interviews as intrusions: First, their goal and their final use is most often the unilateral decision of the interviewer. Secondly, interviewers are often in a superior social position than their interviewees. Pierre Bourdieu et al., *The Weight of the World: Social Suffering in Contemporary Society*, (Stanford: Stanford University Press, 1993), 905.

I asked her if the camera guy can film her going into her house. The camera was rolling as we walked in behind Anita. Once inside, we turned off the camera and I introduced myself to the staff. The staff greeted us in a very friendly manner. However, I saw from her expression that I have some explaining to do. I realized that I was now facing the consequences of not communicating directly with staff. I explained nervously that we were there to interview Anita for a People First of Canada documentary. I introduced Valerie as one of the co-directors. I reminded her that Anita was also a People First member, hoping that since she was a member, the staff would not question her right to participate. With these thoughts in my mind, I continued with my explanation: “We've organized a closing ceremony for The Freedom Tour in Calgary and we're going to film this event as part of the documentary we're making. Anita made plans with me to come along with us to share her story.” The staff appeared to be getting nervous as they realized that Anita had already made plans to leave with us. I now understand that she hadn't felt the need to tell her staff that she was going with us. Had she had the same thoughts as I had had when making arrangements or did she just forget to mention anything? The first one made more sense, how could she just forget to mention it? The staff called someone. Oh no! I began to worry, could they stop her from coming with us? Finally the staff reached someone with authority, probably a residential supervisor or a house manager. “OK, here's the situation, Anita has People First taking her to Calgary but they would also like to do an interview with Anita in Anita's home tomorrow.”

There is a pause as the staff listens awaiting for instructions. I am holding my breath, I feel powerless as I look at the staff holding the receiver.

“OK, so I just thought I would bring it to your attention. OK, no problem.”

I realized that we were at their mercy whether we liked it or not. What could I do if they said no, what could Anita, or Valerie do? I began to regret my decision to not engage with the staff directly. I should have asked them before going there. Now we risked not being able to do the interview with Anita. I began to imagine the worst: “The supervisor said there's a form to fill out to request interviews with residents in the home and it has to be approved. It takes at least two weeks to process the paperwork so you guys will have to come another time.” The staff hangs up the phone, looks at me and then at Anita and says: “OK.” and looks down at her notebook.

I guessed she wasn't too happy with me or with Anita, I don't know. We both bypassed the staff and the agency's authority by making these arrangements. I felt a strange mixture of feelings. I was relieved that Anita could come with us and that we could do her interview in her home. I also felt embarrassed for Anita, since her authority and ability to make decisions had been questioned publicly. I was upset that she had to submit to this kind of control. Who were these people to hold such power over her? With a simple phone call, the interview could easily have been cancelled.

“So what time are you coming over tomorrow?” The staff asked me. I looked at Anita and asked her:

“What time do you get up in the morning?”

“I can get up at anytime.”

“OK, then we'll be here at 9 am.”

I understood this as partly a result of having agencies be both owners and service

providers: it gave them too much power over the residents. The staff were not working for Anita, they were working for the agency and were bound by the agency's rules.

The contrast of experience between interviewing people in their own home and in group homes was remarkable. Experiences like this one highlighted some of the risks of living in a group home or any other residential facility owned, managed and staffed by the same agency. If a filmmaker called me asking me for an interview, as an adult, I have the authority to say yes even though I share my house with nine other people. My family may disagree with the idea of the film but I can arrange to be interviewed in my room if necessary. If my family has concerns about privacy, I can ask that the film crew to not take any images outside my home that would allow people to identify it. In any case, it wouldn't be up to the filmmaker to call my parents or my grandmother to ask permission to interview me in the house. It would be up to me to tell my parents and everyone else in the house. Anita did not need support to understand what she was preparing to do, she understood that she was going to share her story, something she had done before in the past. She chose not to tell her staff, that was her choice, I would have the same option.

Hidden Places: The Saskatchewan Training School Cemetery

Mark, Richard, Bill, the camera operator and I got into the car and headed west on the highway towards Moose Jaw. We were meeting the People First of Saskatchewan gang at the Smitty's in Moose Jaw on our way to the vigil. After a quick meal, we went ahead to get some shots with Bill at the cemetery. I had never been to Valley View before, I had only seen a few pictures sent to us by the advisor for People First of Saskatchewan. We had no trouble finding the place, it was huge and ugly. The main building looked like

a hospital from the seventies. We knew that the cemetery existed, we just didn't know where it was. When I had called Valley View from my home in Winnipeg, the staff people who answered said they knew nothing about it. Now we were there and we had no map, only Bill's guidance. The institution was surrounded by farmers' fields for as far as we can see. How were we going to find this place? We drove around the grounds of Valley View and finally saw two men taking a break just outside some kind of loading dock. We stopped the car and ask them: "Do you know where the old cemetery is?" "Yeah, see that road up there? Just follow it all the way and you should end up there." I was relieved that they didn't ask us why we were looking for the cemetery: how would I have explained it to them? I looked at the road they'd pointed out and saw two barely perceptible vehicle tracks leading off into a field of grass. No sign, nothing. How would we have found this road, if you could call it a road, if those guys hadn't been unloading stuff just as we drove by? This place was in the middle of nowhere. As we arrived, the sky was beautifully clear with a few low wispy clouds and a soft, steady wind. The sun was setting above a statue of a little praying angel. Her eyes looked down, toward the ground. There on the grass, small rectangular plaques were lined up in neat rows. Names and dates like 1951-1962 were engraved on the plaques. Bill made his way to the angel while the rest of us walked around looking at the grave markings. At least people's name had been marked here, I thought to myself remembering our visit to the MDC cemetery at the beginning of the tour.

I read one of the plaques: At Rest, it said. At Rest, yes but I couldn't help imagining what this eleven year boy must have endured during his short life and stay at the

Saskatchewan Training School. Who put those grave markings there? Why wasn't there a sign to let people know about the cemetery? And where was everyone? I received a telephone call and learned that the RV and the cars following it were lost. I tried to give them directions but it was no use, they'd entered the Valley View grounds using a different entrance. I didn't even know where they were! After a long wait and a dozen confusing telephone calls, the rest of the group arrived at the cemetery with a Moose Jaw journalist in tow. They look like a mirage appearing out of nowhere: I was so relieved. Some are Valley View survivors, others are self-advocates and supporters. I saw a musician carrying his guitar. I was doing the sound for this shoot so I could hear a self-advocate from Regina talking to the young journalist: "They didn't want people to know how bad it was in this place. There was a little boy in there, he followed me with his eyes when I went there with other self-advocates, nobody paid any attention to that little boy. We tried to start a People First group in there. Valley View parents got mad and said that that wasn't fair so we never could get a group started." Everyone was asked to gather around in a circle and we repositioned the camera to get a good shot of Tracy Ward, the president of People First of Saskatchewan and their advisor. Tracy began: "The reason we are having this vigil is to grieve our peers who died while living at Valley View. This circle of people is our gift to our friends whose hearts are with us right now. Forgive us because we do not like Valley View Centre and thank you for giving us a choice in life that we can be here and help those that need our help and want our help. Thank you for all the people who gathered around me and around the rest of us as we say goodbye to our loved ones." Candles were being handed out to each person in the circle. Christine helped

Dave light his but the wind was blowing it out. I saw other people struggling with their candles. I thought: “Oh God, we're in the middle of a field in the Prairies trying to light candles!” I looked intently through the video camera viewfinder willing Dave's candle to light. Please, please, please I begged as I thought about the film: these would make beautiful images. Then it happened: Just as the sun went down, the wind stopped blowing, the air became still and the candles were lit! I smiled. The musician started strumming his guitar and everyone huddled closer to him, lit candles in hand and we all sang along. It was absolute beauty, I felt overwhelmed with the joy of being present at such a magical event and profoundly sad for the reasons that had brought us all there.



Fig. 13. “Moose Jaw Valley View Cemetery August 21 2007,”
<http://www.flickr.com/photos/freedomchoiceequality/4727735733>.

The Tour made a stop in Dauphin, Manitoba to meet with Wayne Beever, his sister Valerie, and his two nieces Elaine and Marilyne who I had met and interviewed at the Closing Institutions, Opening Communities Conference. Marilyne helped

to find a venue and send out invitations for the screening. It turned out to be a very intimate gathering. It felt more like a family reunion than a public screening. Kevin stood at the front thanking everyone for attending the screening. He explained how and why the videos had been made and why we were here on this tour. The PFC staff, who was acting

as his advisor for these public addresses, would also say a few words about People First. Once the lights were turned down and the curtains gathered, the power of those personal videos always became more apparent to me as I sat alongside survivors, self-advocates, family members, friends and staff. I would always make my best attempt to intensely observe people's physical, and sometimes barely audible, comments about the videos. These videos very closely reflected each person's own individual style and experiences. Because of this, they didn't follow a predictable style or pattern. I was very proud of this.

Wayne brought his guitar and delighted everyone with his interpretations of Johnny Cash songs. Susie couldn't help herself, and got up from her seat and stood next to him so she could sing too. I just loved how things like that always seemed to happen spontaneously. Although we were all there to talk about serious issues, we always had fun. Thanks to these screenings, we met many family members, self-advocates and survivors. In some cities, we also set up the Video Booths close by, and invited people to speak out about institutions after the screenings. These events mostly took place in Community Living offices since they were willing to let us use the space for free. I was thankful for this. However, in an ideal world, I had hoped to organize these events in local theatres or cinemas like we had managed to do in Winnipeg for the candidates debate. I thought it was important to move outside the usual comfort zones and to use venues unrelated to intellectual disability. I wanted people labelled with an intellectual disability to occupy cultural space where they were not normally expected to be. Unfortunately, the lack of human and financial resources made this impossible in the context of the tour.

Post-Production or Video Editing

Once The Freedom Tour was over, I went back home and sat for hours on end in front of my laptop wearing my headphones going over the tapes we had filmed before and during the Tour. I must have looked through over one hundred hours of worth of material! I did not work alongside the co-directors at this point in the process, I viewed and transcribed the interviews on my own. The sheer volume of material was almost overwhelming to me and, when Kevin offered to sit with me to do this, I simply told him that it would be difficult to coordinate our times since I would be working around my son's nap times, babysitters and during the evenings. Basically, I would try to get the transcription and logging done as quickly as possible.

The advantage of going forward with the NFB for the development of a separate web-based project became obvious as we now had access to the NFB editing suite. We worked to capture and log the tapes from The Freedom Tour. Erika's job was to edit the material into short videos that would be the starting point for the website. Luckily for us, no one else needed this suite and so we continued using it to edit the documentary as well. Using the documentary treatment we had prepared for the NFB (and had been rejected) and the transcription of the interviews, I prepared a roadmap to guide Erika. Admittedly, there was much too much content in the script-like document. I found it very difficult to eliminate certain scenes: I wanted everything to go in there! Although it was Erika's first experience of editing a feature length documentary, she was not daunted and prepared a first assembly and invited everyone in for feedback. It was at this point that the co-directors along with Christine, joined us in the editing room to share their thoughts with

Erika and I on the direction of the film. The editing room was very spacious, and so it was easy to set up chairs in a u-shape behind Erika and the computer monitors.

The process of editing *The Freedom Tour* took about seven months to complete. During this period, the door was open to PFC's national coordinator, the co-directors and myself. We were all welcome to drop by and to see the progress Erika was making. We were very lucky to have her since she took the editing of the documentary very seriously. It would have been difficult to find a person that was willing to invest so much care and creativity into editing *The Freedom Tour*. There was an enormous amount of material from the tour but also from the research and exercises the co-directors and I had done during the development phase. Erika went beyond what most editors would have been willing to do, I know because I have worked with some editors for whom editing seemed to be just a job. Erika was an artist and an activist: she was, without a doubt, the right person for the mission.

Many decisions and compromises had to be made during post-production. For the most part, discussions about the process didn't involve too many differences of opinion. I think it was half way through the editing that we sent a draft copy to the PFC Board of Directors for them to preview and also give their feedback. For the people at the NFB, this was a very strange and risky decision. They thought we should wait until it was more finalized before showing them anything, since they might ask for drastic changes or get attached to things that might not make the final cut. I explained that the documentary was theirs and although this was unusual practice in the film industry, I had to do it. This was a collaborative process after all.

The National Coordinator took the rough copy to the board and brought back their comments. They didn't like the fact that we had included an interview with Christine. During this interview, she shared her thoughts from the perspective of staff working in the community: "Employees make a hell of a lot more [money] working at the institution and that's frustrating you know as a supervisor, we have trouble retaining staff because, I know in other provinces . . . the wages are higher. Here in Manitoba, the wages are low." From my perspective, it was very important to make it clear that decisions to keep institutions open were directly linked to economics and politics not because "some people will always need institutions" as public figures and MDC supporters wanted people to believe. However, the Board didn't want anything in the film about fighting for better wages for support staff. It was their film, their platform to tell the truth of their experience of living in institutions. Staff and other paid caregivers could tell their own stories. Although I did try to argue my point, it was a People First film and their word was final. After this preview, the board asked the National Coordinator to visit the editing suite more often to keep a closer eye on the editing process. Just as in the beginning, it felt strange to speak to the Board through a non-labelled coordinator. I would have much preferred to have one of the members of the Board come down to Winnipeg in person to observe the editing process with their own eyes. This was something we had never thought of before, so there was no money in the budget for that, in fact I still wasn't sure exactly how I would pay for the final sound mix.

It was shortly after the editing process had begun that I went to Saskatchewan to give the very first video making workshop to People First members. In total, I spent seven

days in Regina and Saskatoon to facilitate the process of making personal videos intended for the *Label Free Zone* website. I used a similar approach as the one I had used for developing the film and the personal videos made with the co-directors and Erika. The People First Saskatchewan chapter was responsible for choosing four member to tell their stories using video. I brought the mobile video equipment purchased by the NFB along with me. I felt like Santa Claus showing up with a gift. It was a great feeling! The downside to working far from my home was the time factor. I had much less time to spend with the members to develop their stories. Unlike the videos we made in Winnipeg, we could not go back and forth to make adjustments. Each person had an entire day of filming with me as their facilitator and a local videographer. These workshops were entirely paid for by the NFB. Later on during the year, I would go on to facilitate video storytelling workshops with three more People First chapters across Canada.

I hoped the *Label Free Zone* videos would be self-advocacy videos meaning, that the self-advocates themselves would do most of the talking. They would speak of something that had happened to them personally or had witnessed. As much as possible, I did not want my voice included in these video self-portraits. I really wanted people to stand out in their videos, these were their stories to tell, and I wanted them to take center stage. My questions were only included when it was absolutely necessary for coherence. I was interested in learning about things people did on their own, things they wanted to do on their own, things they were proud of, things they wanted to change, the dreams they had for their futures, their personal outlooks on everything from employment, education, relationships, supported living, artistic practice, self-advocacy. I never worried that

participants might have nothing to say, I knew they did, since their perspectives were seldom heard. Each person's story only further confirmed for me the socially constructed nature of intellectual disability. I will write a bit more about how the *Label Free Zone* videos were made, but before I get too far ahead, I will finish telling you about editing *The Freedom Tour*.

About four months into the editing process, People First Saskatchewan told us about some interviews they had done with Valley View survivors using the video equipment purchased by the NFB. The tapes were mailed to the NFB studio so we could have a look at them. Erika noticed that one of the stories being told in the interview corroborated and completed one we had collected during the tour. Thanks to the People First Saskatchewan footage, Erika was able to create a powerful sequence conveying the desperation these two people felt as they tried to escape institutions, and the power the staff wielded to punish and control their acts of defiance. It was also thanks to an interview done by People First Saskatchewan that the only Native perspective appeared in the film. Although I had a lead on one Native survivor, I had lost contact with him as he stopped attending People First events. I was very thankful for these interviews because I had been struck by the resemblance between Native people's experiences of residential schools with its priests and nuns and labelled people's experiences of institutions with its doctors and nurses. On the surface, institutions and residential schools may have appeared different, but both were based on a belief that there was something inherently defective with these people and that religion on the one hand, and science on the other, could civilize, cure or at least normalize these so-called defectives from a white ableist and

patriarchal perspective.

Meanwhile at Home...Looking for Educational Opportunities

As Erika worked on editing *The Freedom Tour*, I decided I would try to get Stéphane into a literacy program for adults. When I found a program that taught Francophone adults living in the Ottawa area basic reading and writing skills, personal development and computer skills, I thought, it would be a great opportunity for my brother to finally learn how to read and write. I made the telephone call.

Everything sounded great until the woman at the other end asked me a question about Stéphane's knowledge and learning abilities. I immediately had a bad feeling as I realized that I was telling her that he went through Special Education because he was labelled with an intellectual disability.

“Well, this is not a centre for people with mental disabilities” she replied.

“Yes, I understand that but you said that your centre is for all Francophone adults in the Ottawa area. My brother is a Francophone adult living in the Ottawa area.” My heart rate sped up, here we go, here is the catch, I've now hit *the* roadblock.

“Yes, but we don't provide services for people . . . for people who need specialized teaching. I'm sorry but we are just not equipped to help your brother.” I couldn't believe it, actually I could the “I knew it” feeling of disgust and powerlessness took over me. I tried to convince her although I knew it was pointless: As soon as she pulled out the “this is not a service for . . . or there are services especially for . . .” I knew the game was over but I persisted:

“He is capable of staying in the classroom on his own, he might just need a bit more support. Or it might just take him longer to learn but he will learn eventually.”

“Yes, but we also have to think about our clientele. Often, these are older people who are learning to read for the first time. It's hard for them to have the courage to admit that they can't read or write and they might not feel comfortable sitting in a classroom with people with mental disabilities.”

Errr, how could I react to this? My thinking became blurred with anger and frustration, my heart was racing: Was he being excluded from this centre because people might feel...what? Retarded by association? In other words, those poor adults lived with the stigma of illiteracy so we couldn't possibly add insult to injury by including intellectually disabled adults in the program, since that would make them feel *really* stupid! I knew that getting angry at this woman was pointless so I didn't actually say those things, I just thought them. I have been in these kinds of situations before: I can't argue with a person who is not responsible for creating the system that segregates services in this manner. I have to go deeper, I tell myself that this is just what Zizek would call subjective violence: the discrimination that manifests itself as a result of the invisible symbolic and systemic violence. The woman on the other end of the line simply explained to me that people with intellectual disabilities were being served elsewhere by service providers who work with that clientele. She suggested I should get in touch with them. So back to “special services.” So how did this happen again? Labels attributed by the medical body, segregation sanctioned by law¹⁸⁶ and administered by our public institutions. This

¹⁸⁶ For example, since 2008 here in Ontario there is a new legislation that applies to people who, according to this law “have a developmental disability. The new law “talks about services and supports. It also does not use the words "facility" or "institution".” It states that people can *choose* to get direct funding or “*choose* to get services and supports through community agencies”. (italics are mine) Source:

situation reminds me of Arendt's "the rule of an intricate system of bureaus in which no men, neither one nor the best, neither the few nor the many, can be held responsible, and which could be properly called rule by Nobody"¹⁸⁷ What's left for my brother (and the rest of people so-labelled) are substandard educational opportunities offered by day programs. These day programs are where people who are not accepted in mainstream programs get sent to. In most cases, you never graduate or move on from these day programs, you just get old and stop going: you stay at home. This system that consists of waiting lists where there seems to be "no one left who could even be asked to answer for what is being done"¹⁸⁸ is, once again, the invisible violence that Zizek speaks of. This invisible wall is what triggers my anger.

Creating Narration for the Film

As we neared the end of the editing process, Erika agreed that the film needed narration. Until then, she had hoped to avoid it. Perhaps this was a subconscious choice to challenge herself to create a seamless storyline. However, we lacked the visual elements to create this illusion. I had always known that we would need narration to carry the film. Trying to accomplish too many things during the tour without the necessary resources resulted in a few shortcomings such as this one. In one of the very first roadmaps or rough scripts I had prepared for Erika contained narration done by all five co-directors and

<http://www.mcass.gov.on.ca/en/mcass/publications/developmentalServices/servicesSupportsSocialInclusion.aspx>. Can they *choose* to opt out of this system and receive at-home supports offered by the same agencies providing supports to aging people and people with physical disabilities? Can they *choose* to receive supports to attend regular classes and move on to a regular job or regular post-secondary institution?

¹⁸⁷ Arendt, Hannah. *On Violence*. New York: Harcourt Publishing, 1970, 38.

¹⁸⁸ *Ibid*, 38-39.

myself as we travelled along the Prairies. Having so many voices narrating the film just wasn't practical. The audience would be confused! We needed a voice that would help bring the story together. Erika asked what we thought about Mark as the narrator. Although I would have liked a female voice, everyone agreed with using Mark.

The first step to “writing” the narration was to identify the spots in the film that were confusing or left hanging. Erika, myself, and the co-directors all played a role in watching the film and making these suggestions. Once these spots were identified and we (Erika, myself and the co-directors) agreed on the information or the message that needed to be conveyed, I wrote up a list of questions for Mark that, I hoped, would help him say what was needed. Just as I had done for the five personal videos, I used questions and beginnings of sentences to prompt Mark to talk about the things we had the list. Once we were ready, Mark took the bus and met Erika and I at the NFB studio. We set up the video-camera and microphone in the screening room we had used for the digital storytelling workshops. At first, both Erika and I sat there with the sheet of paper asking Mark questions we had all prepared. When that didn't work, I simply asked him if he could remember a certain time during the Freedom Tour. He would then talk about what he remembered, interspersed with jokes, of course, and peppered with his sense of humour. Sometimes it worked, sometimes it didn't. I asked Mark to start his answers by including the questions but this wasn't as easy as it seemed. Mark had to be patient with me as I tried different ways of asking the questions or setting up the scene to help him tell the story we needed for the narration. After quite a bit of video tape, we got what we needed. Of course, that was the easy part, Erika now had to sift through the material and

piece the narration together. By piecing, I mean sentences had to be cut short, intercut with others and moved around. There was a lot of manipulation of the audio.

This reminded me of the amount of work Erika did while editing people's stories. She spent an enormous amount of time editing people's storylines to make them sound "clean." As far as I was concerned, this was something all editors did when working with interviews. We all wanted to give justice to peoples' stories, we didn't want the audience to get distracted by the way the person told his story, we wanted the audience to listen to what the person was saying. As I read through the last chapter of French sociologist Pierre Bourdieu's book *The Weight of the World*, I stumbled upon this explanation:

It is therefore in the name of the respect due to the author that, paradoxically, we have sometimes had to rid the transcribed text of certain add-on developments, certain confused phrases, verbal expletives or linguistic ties (the "rights" and the "ers," etc.), which, even if they give their particular colour to the oral discourse and fulfill an important function in communication (by permitting a statement to be sustained during a moment of breathlessness or when the interviewer is called to support a point), nevertheless have the effect of confusing and obscuring the transcription, in some cases to such a point that it becomes altogether unreadable for anyone who has not heard the original. (...) But we have never replaced one word with another or changed the order of the questions or the progression of the interviews, and all the cuts have been indicated with ellipses.¹⁸⁹

In the case of a film, visual cuts were indicated by the appearance of a new image, but cuts in the audio could be masked by these same images. Although we could not (nor did we want to) replace peoples' words with others, the order of the interviews, of questions and of peoples' stories were often changed to create an overall structure that, although it wasn't chronological, aimed at least to maintain the traditional structure of beginning,

¹⁸⁹ Bourdieu, Pierre et al., *The Weight of the World: Social Suffering in Contemporary Society* (Stanford: Stanford University Press, 1993), 622-623.

middle and end.

Since Erika had understood the project so well and many things were left unsaid or taken-for-granted, I was taken by surprise many months later while discussing some of the *Label Free Zone* videos with an editor. He had had the opportunity to consult with the storytellers to get their feedback on his rough cut, the music they wanted and changes they would like to see. He had incorporated People First members' wishes and now we sat in front of his laptop so that I could view the progress. I noticed that he had left in most of my questions and these linguistic tics and confused phrases that Bourdieu talked about. So I asked him: "Can you take my questions out and do your best to clean up people's stories, I don't want to hear all these hesitations and "uhums."

"But it won't be true to the way the person speaks. I wanted to leave it the way it is so that it's natural," he replied.

I was puzzled, "But hardly anyone speaks as smoothly as they do in a documentary, that's what editing is for. We try to eliminate any noise from the person's narration so that the audience will focus on the content and not on the form." I wasn't too happy.

Was my desire to clean up peoples' dialogue an attempt to trick the audience into thinking that labelled people could actually express themselves clearly? Would their video misrepresent them? Was I trying to use the techniques of editing to infer that they were more intelligent than what most people assumed? Yes, I did because it is true. Was it dishonest? I saw it as taking away "these confused phrases, verbal expletives or linguistic tics (the "rights" and the "ers," etc.)"¹⁹⁰ in order to allow the audience to *hear* the person's story. I was suspicious about the editor's reluctance to see things from my perspective. I

¹⁹⁰ Ibid, 623.

was not aiming to achieve the smoothness of a professional narrator. None of the storytellers had read from written scripts. They responded to prompts or questions developed from the stories they had told during the workshops. At the editing stage, my desire was to strike a balance between each person's way of speaking and the audience's (both labelled and non-labelled) need for clarity and coherence. Anyone who has ever edited video or text to tell a story can vouch that a lot of work is required to create compelling stories able to capture and sustain the audience's interest. It is possible that the editor may have perceived my desire to clean up people's speech as a sort of mutilation of their stories, as Thompson would put it. I saw it as the necessary work to ensure that the person's ability to tell their own stories and speak for themselves would shine through their video. These were video stories, in other words, creative interpretations of people's lived experiences. They were not observational ethnographic documentaries meant to provide "a window" from where the audience could look upon a person's life. These were very personal and subjective stories meant to invite the audience to think *from* the storyteller's perspective and to momentarily engage *with* a People First member as a storyteller. Whether this was achieved in some, all or none of the *Label Free Zone* videos is something you can decide when you watch these videos.

Unfortunately, I never had this conversation with the editor. I wish I had, I could have questioned him further about my suspicions. Instead, I pressed my point and hoped he would "clean up" the videos. When I did receive them on an external hard drive, he had accidentally saved a previous version and some of the final edits were lost. I opened up the Final Cut Pro files and finished the editing myself. I cleaned up the dialogue as

much as I could. I never asked the video storytellers how they felt about cleaning up their dialogue, I made an assumption that they would want to appear as competent and coherent as possible. My decisions were based on my desire to edit, as Bourdieu says, “out of respect due to the author.”¹⁹¹ I hoped an editor would do the same for me if ever I was to be interviewed as part of a personal video. I would also expect, as did the *Label Free Zone* storytellers, to have control over the final edit of the story.

As I continued to think about this particular situation, I wondered if the editor would have hesitated to edit the dialogue of a non-labelled person. What if the person was an expert providing an authoritative perspective on the documentary's topic? Would it be good practice to leave her dialogue as is, with her hesitations, long pauses or unrelated arguments or explanations? It would be true to the way that expert spoke during the interview but would it not undermine her status as expert. It would be more *natural*, however, as a member of the audience, I might wonder if she really was an expert or why her interview had not been edited properly. My *expectations* for a video are very different than my expectations for a face-to-face interaction. I did not expect to watch a person pausing to remember or to think about what they want to say next unless the pause itself carries meaning beyond “oh look, she can't remember what she's talking about.” In my eyes, the magic of non-linear editing is that it *could* be used to allow a person's knowledge to shine through regardless of her ability to meet expected standards of speech. I was aware that editing could easily be used to distort a person's story, but one of the reasons behind the collaborative approach to making videos was to minimize this distortion and misrepresentation.

¹⁹¹ Ibid, 622.

I wonder how Thompson would feel about this. The advantage of video is the inclusion of body language like a sigh, a look in the person's eyes, a shift in body position and other non-verbal information that can be lost or dramatically changed through the process of transcription to text. Thompson could argue that mutilation of the story can still occur because a look or a sigh can be superimposed and associated with a segment of a person's story during which they did not actually sigh or give that particular look. These choices were made at different points in peoples' stories to evoke feelings or to punctuate certain statements. Sometimes edits were made to add coherence to a person's story. Stories were highly edited. Was this mutilation or was it part of the creative process that involves using editing as one of the means for creating evocative and compelling stories? Who decides when a story has been mutilated or creatively rendered? In the case of *The Freedom Tour* documentary, People First members ultimately had the authority to make those decisions. Before screening *The Freedom Tour*, a PFC representative introduces the film: "What you are about to see is not pretty. It is not going to make you feel good. But it is the truth. The truth, told by people who have survived living in institutions."¹⁹²

During the final stages of editing, Kevin made an important contribution. It reminded me of his initial concern of including as many people as possible in the documentary. As he noticed that so many people we had met during the Tour and had taken the time to interview could not be included in the documentary, he made a suggestion: "I think we should see all the people who we interviewed at the end, to thank them for being part of the film even though we didn't use their interview." It was a

¹⁹² Introduction to *The Freedom Tour* often read by the President of People First of Canada before screening the documentary.

wonderful way of thanking everyone. This way they could see themselves in the film instead of depending on someone else to let them know that their name was listed in the credits. I still love watching the credits because of all the beautiful smiling faces.

Before I go on to talk a bit about screening *The Freedom Tour* and reactions to the film, I will describe the *Label Free Zone* video process. Just a few months ago, I visited a group home where I had worked for a few months as a support worker and had this conversation about the *Label Free Zone* videos:

“What do you do outside of work?” asked a staff person.

“I’m writing my thesis in Disability Studies. It’s about video projects I did with people who are labelled with an intellectual disability” The woman looked at me with a quizzical expression. “So the participants must have been quite functional.” This word “functional” grates on my mind, I can’t stand it.

“Well, there were all different types of people who participated in these projects. Some could write a little and could tell their own stories, others were non-verbal and needed more help but they all made videos,” I replied.

“But if they had a disability, they must not have had a mental disability just a physical one, they were able to understand.”

Why this assumption that video is only for people who can speak fast and clearly? I ask myself. Many people including staff and parents, assume that video is just about talking in front of the camera. I try to describe who I worked with, “Some participants were non-verbal and they all were labelled as having an intellectual disability. For the people who were non-verbal or who faced barriers to communication, we depended on their pictures a

lot more. I would also talk to willing family members, advisors and the other members of the group who knew this person. Basically, everyone would share what they knew about the person to help guide in making decisions about what would be in the video.”

“Oh, OK.” She seemed to get it, and appeared reassured.

Once the People First chapters were chosen to participate in the *Label Free Zone* video storytelling workshops, I called the advisors.

“Hi, this is Josée calling about the video storytelling workshop funded by the NFB.”

“Yes, I've spoken to a few people in the group in they would really like to do this, I think this is awesome!” said the advisor.

“It is, I can't wait to bring the video production equipment up to you guys, you get to keep it following the workshop. Just let me know who will participate. Could you encourage people who may not normally get the chance to participate? Often, it's the same people who participate so it would be nice to give a chance to everyone, regardless of their ability to express themselves. Participants don't have to be very verbal, non-verbal people are welcome. I'd like to make sure there's also a good balance between men and women.”

The advisors were paid an honorarium to distribute the information, contact the participants, book a location for the first two days of story development and received a budget to buy snacks for everyone. Advisors were responsible for finding a workshop venue and for making sure four People First members were chosen from their province to participate. Next, I called participants. I found it exciting to call up People First members whom I had never met. When I spoke with them, I would try to imagine where they lived, and what they looked like. An advisor had warned me that I might not be able to

understand Kathleen, one of the members. I told the advisor that I would call nonetheless. I worried a bit about making this telephone call. What if we failed to communicate? Maybe I should not call her at all and wait to see her in person? After all, the advisor did say she was difficult to understand: face -to-face conversations were so much easier. Ignoring these doubts, I finally called Kathleen. As we began our conversation, I was surprised that I could understand exactly what she was saying. After I hung with her, my ego was flattered since I had been able to understand someone who was considered difficult to understand. Was I especially smart or have a “special ability” to understand *those* people? Maybe it was because of my brother. This was not a special ability to understand just a learned habit to stay open and to wait for clarification as the conversation developed. Was Kathleen really all that difficult to understand or did people put up a wall because her pronunciation and pattern of speech was out of the ordinary? The expectation that communication will fail based on assumptions about the speaker is often enough to ensure failure. I have experienced this a young White woman trying to get directions in Tokyo from a Japanese traffic controller. This man could not hear the Japanese words coming out of my mouth because as soon as I approached him, he began waving his arms and shouting “Wakaranai, wakaranai!” I could only assume that he did not expect a Gaijin to speak Japanese nor did he speak English, hence the “I don't know, I don't know!” which effectively put an end to the possibility of an exchange.

To come back to my conversation with Kathleen, it was very clear from our telephone conversation that she wanted to make a video about her job. I could only guess that many people must have had trouble understanding Kathleen in the past, that must

have been why the advisor worried that I might not. I thanked my brother for the years of training he had given me on how to listen carefully when people spoke. It might even be a skill I have developed - to listen broadly, to not get hung up on not quite understanding at first and being patient that if I listen properly, it will make sense. It always *does* make sense, even though words might be missing or ideas might be presented in a sequence that require more effort on my behalf. It helps to see the person as they are talking. Had been in Kathleen's presence, her facial expressions and hand gestures would have given me extra clues to understand what she was saying. I was surprised how well I could understand her without these non-verbal cues.

It was also worth while to contact each participant by telephone to encourage them to think about what they would like to show and talk about in their video. This allowed us to get started right away. I would spend as much time on the telephone as the person was willing to talk. I wrote everything down from family member's names, workplace, friends, hobbies, schedule, whatever they told me. I wrote it all down so that I had a pretty good idea when I first saw them what they were talking about. Also, I could ask questions based on my notes and have the names of people and places handy to help me follow when people were talking. This telephone preparation was not only essential, it was fun. Once we met in person, and the general schedule and format was explained, we could get right down to talking and sharing stories thanks to the telephone conversations. It helped to compensate a bit for having less time to spend on developing ideas for their videos.

Once we met in person and began to develop their stories, I was always excited about the possibilities and terrified that I wouldn't have enough time! During one the

Label Free Zone workshops, the advisor expressed some concerns: “I’m sorry we really haven’t had the time to prepare for the workshop, I wanted to talk to everyone about their ideas before we met here but we’ve been so busy with our AGM so I really have no idea what their stories will be about. How are we doing this?”

“Don’t worry, there was no need to prepare in advance, I talked with everyone over the phone and took some notes. I have a little idea,” I tried to reassure her.

I realized that we were about to embark on a creative process that was completely unknown territory for the advisor. On the day of the workshop, we sat down facing each other. There were four participants and one advisor. The use of pictures during these workshops was very useful. I needed to get to know participants quickly and quite well to help them come up with a video story plan that reflected their personality, conveyed their dreams, goals and or passions and was do-able in terms of time and budget. Although the pictures would most likely not be used in the videos, they remained an invaluable tool during all the *Label Free Zone* workshops for me to establish connections with the participants.

I told participants: “You can talk about anything that’s really important to you. It could be about education, work, relationships with friends or boyfriends and girlfriends, it could be about your job or volunteer work you do or your dreams for the future. You can share a story about something that has happened to you in the past. Maybe it’s something you think might help other people. You guys are the experts about your own lives and that’s why it’s important you be the one to talk about it. Other self-advocates anywhere in the world could learn from your experiences or could be inspired by what you do or plan

to do since your videos will be on the Internet. We just have two days to decide what your video stories will be about. I know some of you already have ideas and we will talk about these. I've asked you all to bring photographs from home to share with the group and to help me get to know you better in this short amount of time. Try to listen when a person is talking about their pictures so that you can ask them questions. We'll all work together to come up with some ideas for each person's video. I will write down as much as I can. Do you have any questions for me?"

"When will we film my video?" one of the participants asked.

"That depends on what you decide to do and if we need to ask permission to film anywhere and if you will invite other people to be part of your video. We need to make sure that everyone is available the day we film your story."

Another participant, as he paced around the room, told me: "I already know what I want to film, I'm ready to get started" Soon, everyone was talking all at once and the level of noise was rising in the room.

"Guys! Guys! We have to plan things out first." I cautioned.

There were only four participants, the advisor and myself, but it felt like there were a whole lot more people in that room. There was a lot of energy!

"Who would like to start first?" I asked, to get the ball rolling.

"I'll start first" said Leanne, one of the younger members as she laid out her four mini-photo albums on the table. I sat next to her and invited the others to sit around her. As she flipped through an album, we saw pictures of her as a baby in her mother's arms, pictures of her playing with her older brothers in the front yard.

“That's my mom, that's my brother when he was six and I was four years old.”

“That's so cute!” Says Karlee, another People First participant. As Leanne happily shared her pictures with us, I took note of her brother's name, her hometown and any comments she made about what she used to be like as a kid. I also took mental notes of the reactions of the other participants in the room. How were they reacting to the pictures? What could I learn about them through this listening exercise? Were there any helpers in the group? Who were the more sensitive ones? Were any of them getting bored and just waiting for *their* turn to speak? I tried to take in as much information as I possibly could about each person. This was the only way I could support them in making some choices about which stories they might want to tell. As Leanne finished sharing stories from her photo album, I noticed one of the participants wandering off to the other corner of the room, muttering in a low voice.

“Sean, you want to show us some of your pictures?”

“What?” he asks from where he is.

“You want to come and show us your pictures?”

“I don't know.” he doesn't look too enthused, so I let it go: “let us know when your ready, OK?”

“Yup.”

Each person took turns showing everyone their pictures. We all had a chance to ask questions about these pictures and to ask what they liked best, what made them the most happy, which people were the most important to them. Throughout these conversations, I took point form notes and made rough drawings on cue cards. I would then show them to

the person. We focused on one person's story idea at a time. Some already knew what they wanted to talk about in their video. For others, it took a bit of talking through pictures and discussions of a practical nature, such as, could we tell this story within the time limits of the workshop? Once each participant had decided what they wanted to focus on in their video, I took more cue cards (or little recipe cards) and sketched out the scenes to check if I had understood what they wanted to show. We would add new cards or move them around depending on how they wanted to tell their story. Finally, I would add dialogue to the cue cards or questions to prompt each participant-storyteller during his/her shoot. Using visual tools like pictures and cue cards to create storyboards was very useful. Sean did finally show us some of his pictures. He didn't have very many, since he had spent lots of time moving from one foster family to the next. He was proud of the self-advocacy work he was doing with People First and the opportunities he had as result of his involvement. After these picture-prompted conversations, we would call family members, support staff or co-workers if we wanted them to participate as characters in the video or if we wanted to interview them. If people could make telephone calls on their own, they did. If they needed help, I or the advisor helped them. Advisors provided a lot of support by acting as a liaison and accessing locations to film certain videos.

Using Re-Enactment to Tell Stories

Kelly had lots to say. She was very active within self-advocacy groups, she loved to

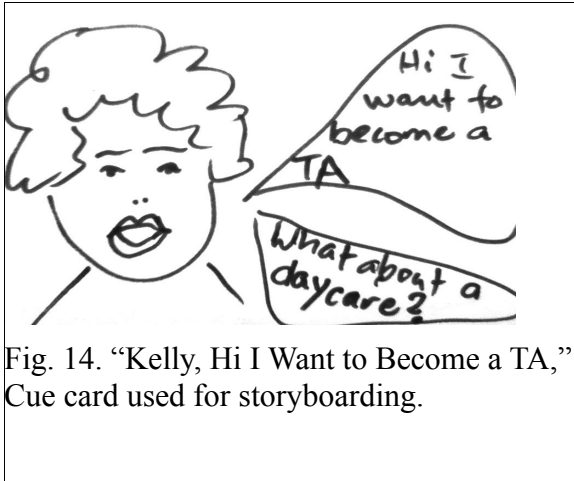


Fig. 14. "Kelly, Hi I Want to Become a TA," Cue card used for storyboarding.

travel and to help others. As she shared some of her pictures with the group, we learned a bit about her family, her friends and some of the places she had been to. As she told us about her goals for the future, my ears perked up when I heard her talking about wanting to become as a teacher's

assistant. I heard how she tried to get support to achieve this goal, but she met a lot of resistance because of her label. She told us about one day in particular when she visited a employment agency for people with disabilities. When she left, she had been redirected to working in a supervised workshop. I scribbled down her words, frantically trying to keep up with what she was saying, coming up with more questions for her. I made some quick drawings (see figures 14 and 15) to begin illustrating ideas for the video: "Wow, Kelly, this is a really important story. You're certainly not the only one who has gone through this." I told her. The other members listened to her story.

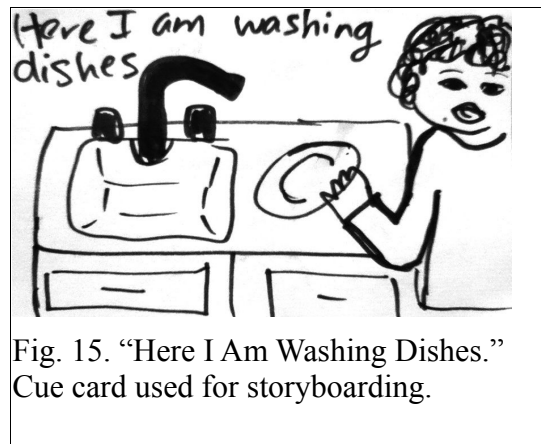


Fig. 15. "Here I Am Washing Dishes." Cue card used for storyboarding.

“How could we tell this story though?” I ask everyone in the room.

“I don't think that agency would allow us to film in their office,” remarked one of the other participant-storytellers.

“No and I don't think an interview with them would work either. We could pretend that you are thinking back about this encounter.” I proposed.

“You could act it out and find someone who would be willing to be the employment worker.” Her eyes lit up when I suggested this.



Fig. 16. “Kelly Cotter.” Video still, <http://www.youtube.com/watch?v=WZvpE9sY-3c>.

“My brother might want to do that.” “That's great, can we call him right now to see if he'll agree to it?” I asked so we didn't lose the momentum. “Yeah, I can call him and I'll call my dad to see if we can film at home.”

This was a creative solution for us to be able to tell this story

without having to confront anyone. Kelly was free to share her experience based on this encounter. I remember it being lots of fun: pretending to be in that moment again and Kelley writing the lines for her brother to play the role of the employment support worker. It was a wonderful way to bring her experience to life. It was a different way of shooting, much more planned and controlled. Kelley had to repeat her lines a few times, just like any other actor. (see figure 16) It gave Kelly the opportunity to tell this story in her own

words and to give her interpretation of her encounter with an employment worker. Once she has finished writing to her Australian pen-pal about this frustrating experience, we see her working in her new “job” at the sheltered workshop operated by the same employment supports agency. Kelly is washing trays in a cafeteria. She turns and looks straight into the camera lens: “Is this all I am qualified for?” she asks the audience. Kelly's story illustrated the low expectations and assumptions made about the capabilities of a person who has been labelled with a learning disability.

Filming with Support Workers Present: It Depends

As I mentioned before, the work of support workers had remained a mystery to me until I began working with People First. Everyone talked about having supports in the community as opposed to living in a total institution. But what did support workers actually do? If I didn't really know, then I was sure most other Canadians didn't know either. During the workshop, Tina had explained to the group that her support worker helped her prepare meals and clean her apartment when she needed the help. She wanted to show people that she lived in her own place and was doing very well. I was excited to film her video, since I thought this would be a wonderful opportunity to show how people could be supported to live in their own homes.

The camera person and I, set up the video camera, the lights, we tested the mic, everything was ready. I took out the storyboards developed during the workshop. We looked at them together:

“Ok, so this is how we are going to start, right?” I asked her pointing to the card with the

number one on and a sketch of Tina cutting vegetables.

“Yeah, I'm over here in the kitchen,” she confirmed.

“I will say 'action' once the camera person is ready. That means you can start preparing supper and we will film you. Don't worry about making mistakes, with the computer it's easy to take out the parts you don't like,” she nodded. When the support worker called out: “Tina, come on, lets get started,” I noticed that Tina tensed up. There was something in the support worker's tone that bothered me. Tina walked over to join the worker in the kitchen. Tina said out loud: “I've got to cut the vegetables first. I need a knife. Where's the cutting board? Oh, boy.” She said as she walked around her kitchen looking for the things she needed.

“What are you looking for?” asked the worker.

“Green beans, I can't find them” she said with a worried look on her face and her support worker responded,

“I brought some over from my place because I noticed yesterday that you didn't have any in your fridge.” Tina grabbed them from the worker and started walking over to the sink.

“Tina? We're going to start filming now, ok?” I asked her from my position behind the kitchen table.

“Yeah, OK.”

“Do you mind putting the green beans back in the fridge? We'll film you looking for them and then taking them over to the sink to wash them.” Tina nodded and put them back in the fridge.

“Camera rolling...action! Ok, Tina you can start preparing dinner and we'll just film you,

go ahead the camera is filming you now.”

She walked over to the fridge and grabbed the green beans, seeming totally unaffected by the video camera's presence. I'm always impressed when people are able to be themselves in front of a camera. I have never been able to do that, I become much too self-conscious, worrying about how I look and how I sound. I asked the camera operator to get some close-up shots of Tina as she was preparing to cut the beans, when I heard the support worker's voice: “No, not like that Tina, here let me show you how to cut them.”

Tina tensed up again, she was wearing a bit of a frown on her face now. The support worker took the knife away from Tina and started cutting: “You have to cut them into smaller pieces like this.”

Tina shrugged and started to look for something else in the fridge. I could feel my senses sharpening and I thought to myself as I observed from behind the camera: “Why did the support worker have to try to correct her?”

“Tina, we're not done cutting the green beans yet, what are you doing over there by the fridge?”

Tina ignored her completely this time. She didn't seem to appreciate the support worker's interventions. Was our presence making them both nervous or was this the way they usually interacted? I had no way of knowing but I did feel uncomfortable. I looked at the camera person to see if he had noticed anything, he looked at me with a “What should we do?” look, and I respond with an “I don't know” look. To me, this was turning into a “What *not* to do” situation when supporting someone. Tina made an attempt to get started with preparing the meat but her support worker intervened again, insisting that she do it

this way instead of that way. I didn't like what I was seeing. Tina's face was now flushed and she was starting to get angry. I was getting worried now since this was supposed to be Tina's day, her opportunity to show people how she lived on her own. I tried to think of a way to get the support worker to leave. I felt bad for Tina who should be enjoying the filming of her video not suffering through it. I had to get us out of this situation so I offered: "We've got lots of material of the two of you working together. I think it would be great to get some shots of Tina alone. What do you guys think about us filming Tina doing a few things on her own now?"

Tina and her support worker both looked at me a bit surprised. It looked to me like they were caught up in the drama that was beginning to unfold.

"Sure, that would be fine, what do you think Tina?"

Tina didn't even answer her support worker, she continued to ignore her. I waited. The support worker offered: "Ok, well I can leave you guys with your work. I've got a few things I can do while you finish up with Tina." The support worker walked away from the scene.

"I think it should take no more than 2 hours," I said.

The support worker casually picked up her purse and jacket to leave. "Bye Tina, I'll see you later!" I couldn't tell if she was unaware of Tina's frustration or if she was ignoring it. Either way, it was as if what just happened was normal. I was left with an uncomfortable feeling: should I have said something? "Hey, you don't need to tell her how to cut those vegetables! What does it matter? It's her house and it's her meal. Just give her the tools, facilitate, *that's* your job!" I didn't go there to criticize Tina's support worker. I went there

to help her make a video about living in her own place. Now that the support worker is gone, I place the cue cards on the kitchen table to review what she had planned to show in her video. I will have to wait for another opportunity to make a video that could demystify the work of a paid support staff.

Screening *The Freedom Tour*

Since *The Freedom Tour* was launched in Winnipeg in the Fall of 2008, it has been screened during many self-advocacy and other disability-related conferences in Canada and internationally. Professors have shown it to their students at universities and at colleges and it has been catalogued in their libraries. I was thrilled to learn that some service providers had begun using *The Freedom Tour* documentary as part of the training for new support staff. The film was also used in advocacy courses given by a community college and in a disability studies course at the undergraduate level. One very moving event was the screening that took place at the University of Toronto to celebrate the closure of the last three large institutions¹⁹³ in the Province of Ontario.

Esther Ignani, from the Department of Disability Studies at Ryerson, attended the screening with some of her students and was moved to write an article. In it, she remarked how she “was struck by how rare it was to watch any film in which so many people with intellectual disabilities were prominently featured —or given so much “air-time.”¹⁹⁴For

¹⁹³ Huronia Regional Centre in Orillia was originally the Orillia Asylum for Idiots when it opened in 1876, Rideau Regional Centre in Smith Falls was called the Ontario Hospital School when it opened in 1951 and had as many as 2, 070 people living there in 1971, and Southwestern Regional Centre in Chatam-Kent was originally called the Ontario Hospital School for Retarded Children at Cedar Springs when it opened in 1961. See: Ministry of Community and Social Services: <http://news.ontario.ca/mcss/en/2009/03/ontario-closes-institutions-for-people-with-a-developmental-disability.html>.

¹⁹⁴ Esther Ignani, “The Freedom Tour,” *Journal on Developmental Disabilities* 15, no. 1, (2009): 67.

me, the film was an invitation for audiences to look at people who have been labelled with an intellectual disability, to see them in action and to listen to their words. I cannot appreciate someone or something without looking intently at them or at it. Bergum and Dosseter remind us that the Indo-European root of the word respect, *spek*, means “to regard or to look again,” while the Latin *spex* refers to “he who sees.”¹⁹⁴ These roots point to the attention that is needed to respect-attention to look again and to actually *see* the other.¹⁹⁵ The video creates a situation where it is OK to look intensely or to stare at a person who has been labelled with an intellectual disability without the risk of being criticized for doing so.¹⁹⁶ It is an invitation to get closer to people who are most likely socially distant.

Having said that, Ignani noticed that there was “little room in survivor stories for understanding some of the sexual and physical contact as consensual expressions of intimacy.”¹⁹⁷ I had thought about this a lot since I read her article and I was curious to know what a person who is labelled thought about this, so I called up my friend Daren and I asked him what he thought about Ignani's comment. Hi first response was to that the film wasn't about that. I said to him: “I guess that sexuality in general, when it comes to people who have been labelled, still seems to be a taboo.”

He replied:

That's why when people ask me about it, I don't talk about it. I keep that to myself. I was asked that by an agency and they said everything is kept confidential and it wasn't. I don't need to go to a stupid workshop. That's not for me, I'm not there to tell a story about my sexual life, that's between me

¹⁹⁵ Vangie Bergum and John Dosseter, *Relational Ethics: The Full Meaning of Respect* (Hagerstown: University Publishing Group, 2005), 69. Italics original.

¹⁹⁶ Rosemarie Garland-Thomson has written an entire book on this matter of social meaning and control: *Staring: How We Look*, 2009..

¹⁹⁷ Esther Ignani, “The Freedom Tour,” *Journal on Developmental Disabilities* 15, no. 1, (2009): 70.

and my girlfriend. If I want to sleep with my girlfriend, that's my business. I had a friend who's mom thought a person with a disability shouldn't be with another person with a disability. I don't why, I'm not a mind reader. I say too bad, I'm doing it anyway, see you later!

We met with our workers [my girlfriend and I]. I felt really uncomfortable and this is something I have never done and I will never do again. We met with them to know the pros and cons but I already knew the pros and cons. It's not up to everybody else to tell me how to enjoy my sex life. I don't tell you [social worker] what do! Oh, uh, you and your husband have to wear a condom. Why are they asking us [as people who have been labelled] to talk about ours? Probably they want to make sure we're being safe and respecting each other but still!

I asked him a question I had a feeling he would enjoy answering: “Do you think people who are not labelled are the authority on safe-sex and respectful relationships?”

“Uh no! How many people did Gene Simmons sleep with?”

I laughed out loud as I remembered the irresponsible things I had the freedom to do.

In her article about *The Freedom Tour*, Ignani also discusses the lack of inclusion of more marginally situated people in the documentary such a GBTL people, Aboriginal and racialized people. This got me thinking about the attempts we did make at including more marginal voices from within the movement. I remember that my main concerns were to include survivors who would be labelled with a profound or severe intellectual disability. Most self-advocates who were active in the movement were, as Downer commented, relatively able white men. Although Valerie and I were concerned about striking a balance between male and female perspectives, none of us in the co-directors nor in the PFC movement, considered non-heterosexual experiences. Ignani's call to use these occasions as opportunities to make these connections across communities and

imposed social categories is one I feel compelled to respond to. The community of people who have been labelled have worked in isolation for too long. The potential “to draws alliances between all incarcerated peoples”¹⁹⁸ should not be missed. Developments in feminist disability theory invite us to draw connections between the pathologization of women, GBLT people, Aboriginal and racialized people by recognizing that disability has been the meta-tag, the ultimate argument used to dehumanize and justify the subordination of these people. In her discussion about the value of experience-based stories written from marginalized standpoints, Stone-Mediatore explains how “Enlarged thought (...) refers to the extent to which a narrative helps readers to test and revise their community's taken-for-granted narrative paradigms and to *anticipate communication* with differently-situated others.”¹⁹⁹ The idea that these stories may give non-labelled people the ability to anticipate communication with people they formerly may have avoided is very exciting. The anticipation of communication creates possibilities for the inclusion of marginalized people within the self-advocacy movement and beyond it.

“Was It Difficult to Work with Them?” The Problem with Assumptions.

Following another screening of *The Freedom Tour* at the War Museum in Ottawa, journalism students from a local college approached me. They were there to cover the event as one of their assignments. One young woman asked me: “Was it difficult to work with them?” I hesitated before answering, trying to choose the right words: “You know, it's funny many people think that it's hard working with people who have so-called

¹⁹⁸ Ibid, 70.

¹⁹⁹ Shari Stone-Mediatore, *Reading Across Borders: Storytelling and Knowledges of Resistance* (New York: Palgrave-MacMillan, 2003): 185. Emphasis in italics is mine.

intellectual disabilities, but in my experience, I've often found it harder to work with people who consider themselves normal.” This assumption that it is so difficult to work with people who have been labelled is very common. I tried to explain that it is not difficult to work with people who communicate differently or learn differently, it's the system (and the unchecked assumptions upon which it has been built), in which they are entangled that makes things complicated.

Negative supports like the Manitoba Developmental Centre, Valley View Centre and The Michener Centre have played an important role in creating and sustaining the assumption that people who have been labelled with an intellectual disability *are* a problem. It was important to try to convey this idea through the film. Bonnie, in her testimony of her sister Judy's experience at the Michener Centre, made it clear, “Down Syndrome is not Jude’s problem, she has these emotional problems that she deals with on a constant basis and still deals with those everyday . . . the horror of what happened in Michener Centre.”²⁰⁰ The availability of negative supports such as institutions, combined with the absence of supports for people who live in the community, continue to construct intellectual disability as child-like, burdensome and undesirable. Portrayal of people labelled with an intellectual disability has not evolved much since the NFB's “Eternal Children”²⁰¹ to *The Forever Child* by the CBC dated November 18th 2012.²⁰²

This video conveyed the perspective of an aging mother and father who were left isolated by the absence of supports. The journalist did not engage with Ryan as a person. She unquestioningly endorsed the parents' understanding of the situation. The journalist

²⁰⁰ *The Freedom Tour*, 2008, DVD.

²⁰¹ *Eternal Children*, The National Film Board of Canada, 1959.

²⁰² *The Forever Child*, Canadian Broadcasting Corporation (CBC), 2012: <http://www.cbc.ca/player/News/ID/2306284333>.

and parents may have been championing the right for caregivers to access better support which was very important, but at the same time, the portrayal of their situation and the title of the video, confirmed stereotypes of people labelled with intellectual disabilities as children, as lifelong burdens, as useless. Something must be done for the sake of these poor normal people who deserved to have a normal life and would have had if they hadn't had the misfortune of giving birth to what American philosopher Peter Singer would consider a lemon.²⁰³ While this type of journalistic coverage may be well-meaning in terms offering a sympathetic portrayal of parents' plight, it elicits only a "Thank god I didn't have one of those!" or "Why can't they just find a place to put him?" type of reaction. Not once was Ryan's subjectivity, his perspective, his needs as an individual even considered, it was all about the parents' suffering. I know this suffering is real from my mother's experience and her friends who are in frighteningly similar situations, but that is not the point. The point is that Ryan's parents will never receive the type of supports they wish to have for themselves and their son if he is not considered a real person, nor will my brother and all the other people who fall into the category of "intellectually disabled." Until our collective "unconscious terrain of habits," as Zizek calls it, continue to conceive of him as a sub-person he will be treated as such. He will receive what is left over once everyone else has been served. How would our understanding of Ryan and his parents' situation be different if we were to see the world from his perspective? Instead of feeling pity for his parents who are left without much hope, would this change of focus to Ryan as the main character (instead of mom and dad)

²⁰³ Read Gail Landsman's article "Too Bad You Got a Lemon" Peter Singer, Mothers of Children with Disabilities, and the Critique of Consumer Culture" in *Consuming Motherhood* edited by Janelle S. Taylor and Danielle F. Wozniak published in 2004.

allow the audience to see this situation as unjust instead of just sad and hopeless?

Meanwhile in My New Home Near Ottawa . . .

After many years of thinking about moving back East to be closer to my family, I finally decided to do it. My family and I had the opportunity to buy a house in a rural area east of Ottawa that was big enough for the nine of us: my grandmother, my brother, my son and my daughter as well as four other family members. Sometimes I wonder: What have I done? Am I crazy? I will never have the time or energy to finish my thesis, let alone make another film, surrounded by all these people! There are just too many people who need support to do daily things and now being a single parent...OK, don't panic, it never helps. Could I become one of those burnt out caregivers? Exhausted and hopeless about my situation, left without energy to do anything to change it? It is a frightening thought. I push it to the back of mind and think: impossible! I must and will find a way. My work with People First members has had a deep impact on my life. I remember talking to a friend about my new intergenerational living situation and telling her: "Well, I couldn't make a documentary about closing down institutions and then send my own grandmother to a nursing home". Maybe it's easy for me to say this since my grandmother is relatively independent for her 89 years. Nonetheless, she needed support for some personal care. I phoned a community health program and found publicly funded support to assist people who need it to continue to live at home. I wanted to get my brother hooked up to this service too! I called the same telephone number and gave all of my brother's information. As I spoke with the nurse on the other end of the line, everything

was going well, I was so proud of myself! I couldn't wait to tell my mother I had single handedly obtained a service for grandma and Stéphane! Then it happened, I'm not sure at what point, probably after she'd asked me to tell her his age and to describe the nature of his needs. She said with a very cheery voice, "You know, I think I've heard of a service point specifically for people with intellectual disabilities. If they provide this service then we can't offer it to your brother. Let me look into this for you and I will call you back with the information." As soon as she said that, I knew it was over. Like Ryan, the doors were being closed to my brother. To me, this was another example of the social costs of segregation and marginalization. She called back to refer me to the same set of services designed to support people who have been labelled. There was nothing new, nothing else available. With just over \$5000.00 per year for Special Services at Home, Stéphane could choose how to use his money. This left him with about \$450.00 per month to pay someone to support him and/or to pay for some type of recreational or social activity. With this money, he could access roughly 5 hours of support per week for a personal assistant receiving \$20.00 per hour. Assuming for the moment that he continues attending his day program, he requires at least 5 hours of support per day to be able to get on with his life.

While working with People First members, I had seen people living in their own places, so I had begun to believe that my own brother could live this way too. I gave my brother and my mother hope that this would happen. I made my phone calls to social workers, service coordinators and agencies providing supports. Before long, I could feel my blood pressure rising along with my frustration, "What are these people doing if they

can't help get better supports for my brother? What *is* their job?" I had witnessed my mother's frustrations with the system so many times, but still believed that if I just talked to the right people, maybe something would happen. Nothing did. I couldn't help but feel that the entire system was just there to recreate itself as well as more employment for its non-disabled and non-labelled employees. Wolfensburger said that: "over the long run, organizations serve themselves more than they serve any other purpose."²⁰⁴ Although his remark sounds defeatist, it is not. It simply points to the need to focus on the assumptions that have led to this self-serving situation. To base services on the assumption of incompetence or on a radical biological flaw justifies the creation and maintenance of substandard segregated systems of support services. There are exceptions to this rule but they remain exceptions. Why fund these services properly since they are for defective people who are lucky to have a roof over their heads and a place to go to? People who are labelled with an intellectual disability are no more incompetent than anybody else: they just need support (not supervision) to get on with their lives.

For my brother, the search continues for his own place and greater independence. He continues to attend the same day program he has for the past twelve years. My mother remains his primary caregiver. He lives on his monthly allocation by the Ontario Disability Support Program (ODSP). Although the Province of Ontario is moving towards individualized funding through its Passport Program, the waiting lists to access money move at a snails' pace if at all. In the Spring of 2010, my mother contacted my Stéphane's ODSP worker to get him onto a waiting list for an interview to establish the types of

²⁰⁴ Wolf Wolfensberger, *A balanced multi-component advocacy/protection schema* (Toronto: Canadian Association for the Mentally Retarded, 1977), 4.

supports Stéphane needs. Following this interview (which he still hasn't had as of January 2013), he will continue to wait for additional individualized funding. Just as Saskatchewan People First member Dwaine and his sister Diane (see figure 17) discussed individualized funding and accessible housing in his video:²⁰⁵ “It could be a month, it could be a year,” they don't know. “In the 2010/11 fiscal year, 2,700 people received a total of \$31 million (or an average of \$11,500 each) in Passport funding. In addition, there were approximately 4,500 people who had been determined to be eligible, but who, because of the limited funding available, were on the Passport funding wait list.”²⁰⁶ I'm not very good at math but doesn't that mean that 63% of people who were eligible were simply put on a waiting list? How were they determined to be eligible? Had they already been through the interview? The names of services change to things like Passport and individualized funding. New offices are opened, new staff is hired, but the people needing the supports continue to wait for the changes to allow them to get on with living their lives. I must fight the urge to become too cynical when I think about these things.

The Freedom Tour Legacy

So where are things now in relation to *The Freedom Tour*? Two provincial People First chapters have decided to make *The Freedom Tour* process their own. In 2010, Prince Edward Island People First organized their very own Freedom Tour. I called up their office in Charlottetown up to learn more. Melissa Good, the advisor, was proud to tell me:

²⁰⁵ Watch Dwaine Scott's video here: <http://www.youtube.com/watch?v=QL0Ts3ERl14>.

²⁰⁶ 2011 Annual Report of the Office of the Auditor General of Ontario on Supportive Services for People with Disabilities by the Ministry of Community and Social Services, 294. Thanks to sibling activist Leah Dolmage for passing on this information.

We showed the film at one of our meetings, literally everyone unanimously said we have to do it here. Members were really excited and wanted to do something about people (labelled with an intellectual disability) living in manors, community care facilities for elderly people and in large group homes. People First members, with the support of advisors, organized workshops for labelled people across PEI to talk about their current living situations. We divided people into working groups and asked questions like, “Where do you live? Why do you live here?” We wanted to get a picture of the situation and to make it public, to show that this is not happening in the 1950s, it's happening right now in 2012.²⁰⁷

“Did you guys encounter any barriers to organizing these workshops?” I asked Melissa.

Of course the roadblock was that some of the group homes thought we were the big hairy monsters saying that they were the institutions, they felt threatened, we had to be smart in the way we presented ourselves. A group home isn't necessarily a place with 100 beds. When you look at a definition of an institution, they didn't choose to live here, to cook, to do this . . . people from the group homes would come, quite a few members had been in group homes their entire lives and we had to be respectful because they liked their group homes.

“How did you guys deal with that?” I wanted to know.

I would call the people at the group home to tell them that a resident wanted to participate in the Freedom Tour and reassured them that they liked living there. These group homes allowed their residents to come to some meetings but when it came down to the very day of The PEI People First Freedom Tour, the staff didn't let the residents out. We had the bus there waiting for them outside, and they had their T-shirts. We would call the group home to pass on information and the staff would say so and so can't come to the phone right now and they wouldn't pass on the information to that resident. We ruffled some feathers for sure, we were criticized for our message.²⁰⁸

Melissa and I continued to talk for a while. She explained how they wanted to make more videos about people living in the community with proper supports to show how it can be done. They plan to organize Our another Freedom Tour on P.E.I. to see what had or had

²⁰⁷ Melissa Good, Telephone conversation with Josée Boulanger, November 28th, 2012.

²⁰⁸ Ibid.

not changed for people labelled with an intellectual disability.

P.E.I. People First showed their videos to the other maritime chapters (Nova Scotia People First, New Brunswick People First and People First of Newfoundland and Labrador) as a challenge to organize and film their own Freedom Tour. People First of Nova Scotia responded and are currently in the process of finding adequate funding, and of getting to know a filmmaker who has agreed to work with them.

I called up Richard Ruston, who had been on the original Freedom Tour, to read him the passages in my thesis where he is mentioned. After going over the material, we talked a bit about the PEI and Nova Scotia People First tours, Richard said: “Still today people are being controlled in the community and in institutions. The missing link is all

the people that died and everybody that are still in institutions. By travelling across the Prairie provinces it made that link [between people] a little bit stronger. I think that people are starting to speak more on their behalf now. It's important that we



Fig. 17. Dwaine Scott. Video Still, <http://www.youtube.com/watch?v=QL0Ts3ER114>.

don't forget it [institutions] so we don't repeat what we did years ago. We don't want to see people go through what we went through.”



 PEI People First Tour - Chapter Two Planning

Fig. 18. “PEI People First Tour – Chapter Two Planning,” Video still, <http://vimeo.com/40360495>.

“What do you think we could have done differently during the tour?” I asked him.

“Students from the DSW (Developmental Services Worker) programs should have been there because they are the future.” said Richard.

I agreed with him. Students

could have learned so much from attending the tour screenings and participating in the post-screening discussions we hosted along the way. But for Richard, who is an experienced self-advocate and public speaker, “a book is better because they [students] have to take the time to read it.” As for me, I continue to favour the multimodal nature of video, I just think that experience-based stories need to get to the right people.²⁰⁹ Future support workers are among these people.

In terms of media, things are very different now in 2013 than they were in 2006 when I first approached People First of Winnipeg. Back then, I didn't even know about Youtube.com and Facebook.com. Now, I use these social media sites, as well as Twitter, to share videos, pictures and articles. People First of Canada has been on Facebook since

²⁰⁹ This conversation reminded me of Wang's advice: “recruiting the policymakers and community leaders who can be mobilized to help implement the change recommended by photovoice participants.” Key community members, service providers and political representatives were informed of the photovoice project from the very onset. The dialogue must be actively sought, an audience must be built from the beginning and people with the power to make changes must be kept informed of the project. Wang, Caroline C., “Using photovoice as a participatory assessment and issue selection tool: A Case Study with the Homeless in Ann Arbor,” in *Community-Based Participatory Research for Health*, ed. M. Minkler and N. Wallerstein (San Francisco: Jossey-Bass, 2003).

2010, People First of Manitoba since 2011, People First Saskatoon since 2012. People First Nova Scotia has their own Youtube.com account and PEI People First is on Vimeo. Having so many video stories and images in the public realm has made it easier for me as a researcher and a storyteller. The content created and posted on the Internet by People First members and other self-advocates shows a different perspective of intellectual disability. The stories are out there.

Chapter IV: Lessons Learned

In the previous chapter, I told experience-based stories about the collaborative work I did with People First members primarily to make *The Freedom Tour* documentary, but also some experiences drawn from the *Label Free Zone* videos. I also briefly revisited my experiences of growing up with a brother who has been labelled with an intellectual disability. Throughout the story, I have made connections with the work I was involved in and my own personal experience with disability. Through that exercise, I also hoped to gain insights into my understandings of intellectual disability and the impact this has had on the approaches I adopted. I also hope to gain some insight into the effects of being both an insider as a sibling and an outsider as an able-bodied (for the moment), home owning, white woman with a university education. In other words, recognizing my own privileged position and authority as the older and so-called normal sister.

This chapter will discuss and summarize the lessons I have learned from writing this auto-ethnography. I will discuss auto-ethnography as a method of inquiry to reach the goals I had set for this study. I will make an argument for collaborative experience-based storytelling based on the theory of Stone-Mediators. I will look to Goodley's ideas on capacity and bell hooks to discuss the importance of assuming competence. I will talk start from an assumption of competence and a relational perspective to discuss collaboration, respect and empowerment. I will also discuss Griffith's advice to exercise “constant vigilance” in relation to my work as filmmaker/facilitator and researcher. I will discuss the risks of positioning oneself as an advocate. I will discuss the impact of my

own situatedness as a non-labelled older sibling and the place for anger. Finally, I will end this chapter with a discussion about video as medium of representation.

The Case for Experience-Based Stories

Burnett's criticism is important in clarifying the value of experience-based and collaborative videos: "there has been a lack of critical and evaluative work done on the videos themselves, although there are many descriptive examples that end up justifying the use of video as a tool of community development and consciousness-raising."²¹⁰ First, Bourdieu talks about the importance of "making generally known": "One has to acknowledge the effect it can have in allowing those who suffer to find out that their suffering can be imputed to social causes and thus to feel exonerated; and in making generally known the social origin, collectively hidden, of unhappiness in all its forms, including the most intimate, the most secret."²¹¹ These collectively hidden social causes resonate with Zizek's ideas on invisible systemic and symbolic violence "since they sustain the zero-level standard against which we perceive something as subjectively violent."²¹² Experience-based stories change the backdrop against which we begin to analyse a situation. As public documents, *The Freedom Tour* documentary and the *Label Free Zone* video stories send a message to other survivors, to self-advocates and to their families that "It's OK to talk about these things. You're not alone. Something has to

²¹⁰ Burnett, Ron, "Video: The politics of Culture and Community," In *Challenge for Change: Activist Documentary at the National Film Board of Canada*, ed. by Thomas Waugh et al., (Montreal & Kingston: McGill-Queen's University Press, 2010), 369.

²¹¹ Bourdieu, Pierre, et al., *The Weight of the World: Social Suffering in Contemporary Society* (Stanford: Stanford University Press, 1993), 629.

²¹² Slavoj Zizek, *Violence: Six Sideways Reflections* (New York: Picador, 2008), 2.

change but don't be fooled: it's not you.” As Senehi et al. Reiterate: “Storytelling in support of advocacy is inclusive; fosters shared power and mutual recognition; creates opportunities for openness, dialogue, and insight; and brings issues to consciousness. Storytelling is sometimes a means of resistance and the journey to social justice. Such storytelling builds understanding and awareness, and fosters voice.”²¹³

Through these experience-based stories, labelled people's knowledge is used as the raw material for pointing out problems that (temporarily) non-disabled people might never notice. These video stories are valuable because they speak from a perspective that is a normal part of the human experience that is seldom acknowledged as such. Stone-Mediatore proposes a compelling argument in favour of experience-based stories:

the epistemological virtues of living in a socially or culturally marginalized position include, for instance: a daily experience with the obscured costs of social contradictions, a shifting in and out of cultural worlds, an engagement in activities that defy the dualisms and exclusions of received analytic categories, and a resistance to the social relations that ruling beliefs present as 'natural'.²¹⁴

When I first started with People First members, I could only explain the importance of making their stories heard as a need to “add some balance” to the misleading dominant stories circulating about people with the label of intellectual disability. By adding their voices to the stories (in case histories, medical texts, news, literature, etc) being told about them, it would help to tip the balance. The collaborative approach (or participatory as Burnett names it) would add to the argument of capacity. This is how I have always perceived the role of activist media: adding a drop of truth in an ocean of misinformation.

²¹³ Senehi et al., “Dreams of Our Grandmothers: Discovering the Call for Social Justice Through Storytelling.” *Storytelling, Self, Society* 5, no. 2 (2009): 96.

²¹⁴ Shari Stone-Mediatore, *Reading Across Borders: Storytelling and Knowledges of Resistance* (New York: Palgrave-MacMillan, 2003), 184.

But this additive function, as Stone-Mediatore has mentioned, is limited since it simply pits one truth-claim against another truth-claim (or Zizek's subjective violence) without solving the very real problem of unequal social positions and cultural capital (or Zizek's systemic and symbolic violence) which affect, although very differently, labelled people, researchers, support workers and medical and social work professionals. I find that Stone-Mediatore's explanation of the value of experience-based stories is more convincing. Instead of arguing that “my view is better or more truthful than your view,” Stone-Mediatore proposes recognizing the value of experience-based stories based on the fact that only the people who resist the social relations (sometimes by simply trying to be themselves) that ruling beliefs present as “natural” can contribute to redefining analytic categories and expose the human costs of social contradictions. The value of experience-based stories lies in the very fact that they stem from marginal standpoints. Now that I have a better understanding of the value of collaborating to make these stories, I will talk about my own experience of writing personal stories as part of this study.

Writing About the Auto-Ethnographic Writing Experience

“There is a need to exercise a constant vigilance, together with a continuing willingness to dream the impossible. One way of doing this is regularly to ask some difficult, challenging questions about what is being done.”²¹⁵ It has been important to take a step back and to reflect on my work and on my personal experiences of disability. The approach of writing an auto-ethnography has allowed me to do so.

²¹⁵ Morwenna Griffith. *Action for Social Justice in Education: Fairly Different* (Maidenhead: Open University Press, 2003), 60.

The most difficult part of writing these stories has been the moment when I am faced with reading it to a person named in one of my stories. Relational ethics, with its emphasis on the impact of decisions and acts on relationships, helped me to acknowledge the primacy of protecting relationships when writing about my experiences. I didn't realize, until I actually had to do it, how uncomfortable it might make me feel. I read about Carolyn Ellis' discomfort but to be honest, I had to try it to understand it. I felt a strange sort of embarrassment. It was very difficult to read the story out loud because I saw how my words took on an entirely different meaning now that the person was listening to me read through these stories. I also saw how I lost control of the meaning of my words and that they could be interpreted in ways that I had not intended. I do not think that this anguish will ever leave me, I simply have to live with it. Sarah Wall talks about the anxiety she felt when writing an auto-ethnography about her experience of adopting a child: "I had a persistent and significant sense of anxiety about the tension between proceeding with an academic project and telling a story about my life that was inextricably intertwined with my son's."²¹⁶ She has yet to publish her auto-ethnography. The anxiety I have experienced while writing these stories has mainly been caused by the realization that sharing my experience as filmmaker/facilitator and sibling involved so many other people. It was at times impossible to tell a story strictly using the "I" since it would be factually incorrect. I had not realized how complicated it would be to tell these stories without using the "we" in certain situations. I was careful to use the pronoun "we" in descriptive situations such as "As we arrive, the sky is beautifully clear with a few low

²¹⁶ Sarah Wall, "Easier Said than Done: Writing an Autoethnography." *International Journal of Qualitative Methods* 7, no. 1 (2008): 49.

wispy clouds and soft but consistent wind.” Writing from a personal point of view was much more complicated than I had anticipated. Questions of voice, implications for the people in my life became apparent only as I read the passages out loud to them. Some I still feel slightly uncomfortable with but I have accepted to live with a certain level of discomfort. These issues have inspired to look for other methods of telling stories and I will talk about fiction a little further as a less risky way of telling stories that deal with very personal, sometimes difficult situations and serious issues.

Writing this auto-ethnography and discussing it with friends and family forced me to acknowledge that within my own family, my brother does not occupy the same social position as I do. Now that I write this, I realize that this is most probably obvious to outsiders. Somehow, I have not given it much thought before. Family members may love him and wish the best for him but when it comes down to his right to take part in decision making that involves housing issues, he is not included. Decision making power in my family is clearly based on ownership. My brother is not one of the owners of the house. He is considered, I suppose, a tenant or a dependant that must go along with the owners' decisions. His only protection is that we love him and try to make decisions that will have positive effects on his life. Despite these good intentions, as an adult he has not had a say about where he lives nor with whom. Whether he likes it or not and, for better and for worst, he lives with his family where he is not considered to have the competence to participate in decision making. As my mother has said “When you live under my roof, you live under my rules.” Although it would be ideal from my parents' perspective, I am not expected to live under their rules. If I have not succeeded in convincing my own

family to include him as a legitimate decision maker, how can I expect strangers to do it? If I succeed in helping him to find a place to live away from our mother for the first time, how will I ensure that he is respected and taken seriously by the new people who support him? There is a risk that the same pattern of 'living under someone's roof' may repeat itself. Although living arrangements may now be called 'home share', it is based on a foster family-like model. The non-labelled caregivers take over the role parents once occupied with a few differences such as receiving a daily stipend and the services of a social worker by a local service provider. I know that the problem stems from the fact that he lacks the money to pay for the supports he needs. He is forced to depend on other people's good will to support him. This financial dependence mixed with people's ideas of what is acceptable and not acceptable for him to do really limit his choices in life. In other words, his lack of financial resources which are justified by a view of a so-called intellectually disabled person as an anomaly make him vulnerable to control.

I, on the other hand, have had a long list of opportunities to work, to travel, to have children and to continue my education. I have had the freedom to make all kinds of choices. The little gains I have managed to share with my brother have been the opportunity for him to create his own personal video²¹⁷ where he clearly states that he wants a place of his own and a job working for public transit. This video is a public document by him talking about his wish to live on his own and to have a job. When we moved out to this big house outside of Ottawa with the rest of the family, I went with Stéphane to a local agency supporting people who receive the Ontario Disability Supports Program to find a job. I sent his video to the agent helping him to find work to show her

²¹⁷ To watch his video, go to: <https://www.youtube.com/watch?v=E3SUxK66blk>.

that Stéphane's wishes were clear and they were public. He did finally get a job at a local transportation company. It is a small victory: one hour of work per week paid at minimum wage but it is a step in the right direction. All of this to say that just as there are difficulties in positioning myself as an advocate when working with people who have been labelled, there are difficulties in taking a step back from my own personal situation to see the contradictions existing between the way I wish things were and the way they are. The back and forth process of writing and discussing these stories with others has helped me to spot some of my own limitations as an activist. The wonderful advantage of observing these limitations now creates the possibility of finding solutions to move beyond them. I can acknowledge and take pride in the knowledge and skills I have acquired as a result of my close relationship with disability. "Like any siblings who can grow up to have a deep identification with one another, siblings of children with disabilities can develop strong identification with disability issues."²¹⁸ This strong identification has led me to recognize the discrimination and has resulted in adopting an attitude of moral superiority. However, if my goal is to bring about social change through storytelling, I must be mindful about my perspective and continue, as Griffith suggests, to "ask difficult questions, challenging questions" about the work I am doing and how I am going about it and to "exercise constant vigilance."

²¹⁸ Rhoda Olkin, *What Psychotherapists Should Know About Disability* (New York: The Guilford Press, 1999), 108.

Experience-Based Storytelling With/By People Who Have Been Labelled: “The Same But Different”²¹⁹

Experience-based storytelling for people who have been labelled with an intellectual disability is the same as it is for any other person or group of people who experience marginalization. What makes it different is the need for a collaborative or what Walmsley calls a “team approach.” This need for human supports complicates things. Human support is “much less amenable to control than technology.”²²⁰ It is much easier to adapt a wheelchair, a vehicle, a computer or even a guide dog to suit a person's needs than to do this with a human support worker. Each person comes with their own perceptions and assumptions, as I did when I first started working with People First members.

I think there is a need for a fundamental change of habit. Even as People First members shout “We can do it!” the assumption of incompetence lives on.²²¹ When I explicitly adopt a collaborative approach to work with labelled people, this attitude is supported. It is impossible to collaborate with people who we assume to be incompetent. Why would anyone want to do that? In a collaborative approach, there is an assumption that people are competent: that is the starting point. An experience-based narrative made collaboratively in a context where labels are questioned, not accepted, and where competence is assumed not undermined, creates an opportunity to build a relationship of

²¹⁹ I borrowed the phrase “Same but different” from Jane Seale, “The Same but Different: The Use of the Personal Home Page by Adults with Down’s Syndrome as a Tool for Self-Presentation,” *British Journal of Educational Technology* 32, no. 3, (2001).

²²⁰ Jan Walmsley and Kelley Johnson, *Inclusive Research Methods with People with Learning Disabilities: Past, Present and Futures* (London: Jessica Kingsley Publishers, 2003), 54.

²²¹ I think that Dan Goodley leads the way in terms of deconstructing the notion of intellectual disability. See Goodley (2001).

mutual respect with a person who is labelled both through the process and the product. By listening to the stories told by labelled people, non-labelled people engage in supportive relationships with people who have been labelled, and they are invited to question their taken-for-granted assumptions about labelled people, as a result to question their habitual ways of interacting. This is an on-going process, it is a constant battle since we are all fighting against such long held beliefs.

According to Goodley, collaborative methods are based on a capacity model instead of a deficit model.²²² This assumption of competence is an invitation for the system of service provision, from ministries of social services to the agencies and workers on the front line, for families, artists, medical professionals and academics to question the use of the word “therapy” that qualifies many of the activities offered to people labelled with an intellectual disability. For example, there is music therapy, dance therapy, art therapy, zoo therapy and so on. Offering music therapy (instead of just music classes) as an option within a day program is based on a deficit model with an assumption that something about someone needs to be fixed. On the contrary, an inclusive approach to research (or creative production) assumes that labelled people are competent. As reminder, I list Walmsley and Johnson's principles of inclusive research:

- The research problem must one that is owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities.
- It should be collaborative – people with learning disabilities should be involved in the process of doing the research.

²²² Dan Goodley, *Self-Advocacy in the Lives of People with Learning Difficulties*. (Maidenhead: Open University Press, 2000): 181-182.

- People with learning disabilities should be able to exert some control over process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.²²³

These principles talk about ownership, advocacy, collaboration, control and accessibility. There is an assumption that labelled people are part of the research process of production, instead of being an object of therapeutic intervention. In the context of experience-based video storytelling, Goddard talks about “Autobiographical video [as] a self-generating practice that re-invents an ensemble of subjectivities as much as it re-invigorates the genre . . . The treatment within this general practice promotes a restorative sense of healing because it is self-prescribed and self-administered.”²²⁴ Although Goddard speaks of treatment and healing, he makes it very clear that this is possible *because* it is self-administered. The choice of topic and the process of exploration is under the control of the storyteller. When personal video storytelling is not self-administered, it becomes yet another intrusion into person’s personal life. Although *Label Free Zone* participants were self-elected by themselves or their local chapter, I remember not feeling comfortable with a participant's choice to remain in a supervised living arrangement. I thought he should be living in a less restrictive environment: I wanted him to be more independent! I was frustrated by his acceptance of an environment that I saw as too restrictive, as controlling. But his life was not my life, and I was really only passing through. He had found the best situation for himself with the resources he had available in his community. I had to accept that this was my dream, not his and I needed to shut up before risking to make him feel

²²³ Walmsley and Johnson. *Inclusive Research Methods with People with Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley Publishers, 2003: 64.

²²⁴ Steven Goddard, “Anecdotes and Antidotes – Stories as Balms, Storytelling as Healing,” *Art and Pain*, issue 4 (Winter 2003): 11. http://www.doubledialogues.com/archive/issue_four/goddard.htm.

that I thought he was not competent enough to make choices for himself. By assuming he was competent, I could not logically begin to undermine his choices by imposing my views of what I thought he should be doing with his life. He was fully aware of the options available to him and knew better than I did his abilities and limitations. In situations like these, where it is tempting to tell someone what to do, I must remember that “respect requires not so much refraining from interference as recognizing our power to make and unmake each other as persons and exercising this power wisely and carefully.”²²⁵ I may question people's choices while continuing to relinquish control: this is their story, not mine.

Believing in people's abilities is also something that bell hooks recognizes is at the root of letting go of control: “The bottom-line assumption has to be that everyone in the classroom is able to act responsibly . . . All too often we have been trained as professors to assume students are not capable of acting responsibly, that if we don't exert control over them, then there's just going to be mayhem.”²²⁶ The irony is that this attempt to control is what creates mayhem such as support workers standing over people shouting in their faces, while they point and shake their fingers inches away from people's noses. These types of behaviours continue to happen and be tolerated in sheltered workshops, crowded day programs and group homes. Anyone who has visited or spent enough time in any of those places will have observed these types of behaviours. In a day program, when people's behaviour was considered undesirable, they were often told to sit down, calm

²²⁵ Robin Dillon, “Respect and care: Toward moral integration,” in *Respect for the elderly: implications for human service providers*, ed. Kyu-taik Sung and Bum Jung Kim (Lanham: University Press of America, 2009), 30.

²²⁶ bell hooks, *Teaching to Transgress: Education as the Practice of Freedom* (New York: Routledge, 1993), 152.

down, or sit up, not lie down, and so on. But as I read Melanie Nind's article²²⁷ about “stereotyped behaviour”²²⁸ which can take the form of rocking, hand-flapping or twiddling string or fluff, it confirmed a feeling I had about interpreting these behaviours as expressions of resistance. I appreciated the positive twist it proposes on the interpretation of behaviour by people labelled as having profound intellectual disability. So, to come back to the assumption of the need for therapy, I like to believe, as Melanie Nind is proposing, that the 'stereotyped behaviour' is an expression of resistance either to overstimulation, as is the case in the day program and lack of stimulation because of the lack of engaging and challenging activities offered to people who have been labelled with a profound intellectual disability. Sometimes it is an expression of frustration at something we, as the people sitting next to him, have failed to understand or to interpret.

It is still common for community college programs designed to prepare future support staff to start from a deficit model. For example, the local French community college's program geared at preparing students to support people is entitled *Interventions with People with Disabilities*. The banner photograph includes an image of none other than my brother dutifully painting alongside his friend, with a support staff dutifully looking over their shoulders.²²⁹ My brother does not even like painting. He enjoys playing pool at the local bar, bowling, soccer, watching videos on Youtube.com and chatting with

²²⁷ Melanie Nind, “Stereotyped Behaviour. Resistance by People with Profound Learning Difficulties,” in *Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance*, ed. Duncan Mitchell et al., (London: Jessica Kingsley Publishers, 2006): 202.

²²⁸ “stereotyped behaviour” is one of the behaviours listed in a community college program as modifiable using scientifically validated methods of intervention. Viewed from Nind's idea of resistance, it is frightening to think of all the students paying to learn to work with people who have been labelled who are being misinformed and under-informed about the possibilities of interpretation of behaviours that are not considered normal.

²²⁹ See: <http://www.lacitec.on.ca/programmes/51059.htm>.

his girlfriend on the telephone. However, the image conveys the type of relationship that is to be encouraged between staff and labelled people: it is one of supervision while people labelled with an intellectual disability take part in appropriate activities such as arts and crafts or perhaps this was considered an art therapy session. Courses on behaviour modification will teach students “scientifically validated intervention techniques.” If I were hiring someone to support me, this is not the knowledge and skill set I would be looking for. I would prefer to hire a person who assumed I was competent enough to know what I liked, what I needed and what I wanted. By shifting from a deficit model or medical model of intellectual disability to an assumption of competence, this way of thinking is possible. It opens the doors to building relationships based on mutuality.

Support workers or facilitators who work with people who have been labelled may become what Seale calls ““mediators” in the process of self-presentation.”²³⁰ Although all creators of personal video or digital stories are at risk of more powerful figures mediating, people who have been labelled may be at an even greater risk because of the assumptions about them and, because of paternalistic attitudes towards them and communication barriers. Seale elaborates:

Teachers are in an ideal position to help with the technical aspects of publishing Home Pages and might be assumed not to have a vested interest in the nature of self that people with Down Syndrome wish to present. Nevertheless teachers, just like parents, can be viewed as powerful “authority figures”. Therefore their involvement in helping people with Down Syndrome to manage their identity may need to be carefully

²³⁰ Jane Seale, “Researching home page authorship of adults with learning disabilities: Issues and dilemmas.” In Proceedings of International Education Research Conference AARE-NZARE, Auckland (New Zealand, November 30 - December 3, 2003): 4.

considered so that they do not use their power and authority to place people with Down Syndrome in a role of dependence and passivity.²³¹

Just as Seale cautions teachers or parents as authority figures to not use their power abusively, this could also be said to support workers, educational assistants and filmmaker/facilitators. How can people in these roles avoid this abuse of power during the creative process? As Walmsley puts it “the key issue here is power . . . people with learning difficulties still rely on a team approach, and few have been able to argue that without this team approach, people with learning difficulties would be in a position to research and publish.”²³² The issue of power was brought up in an evaluation of Acting Up's Multimedia Profiling projects as an “issue relating to consent to profiling . . . related to how far family views should be respected, despite the family having no automatic legal right to veto an adult’s activities.”²³³ A teacher's, a parent's or a support worker's interests may not always coincide with the interests of the person who is labelled. Who decides in these situations where we, as facilitators, are not able to determine if the person who in favour of the video storytelling process? If we ignore these questions, we also ignore the people who face big barriers to communication. This is a serious discussion that needs to happen between self-advocates, substitute decision-makers, family members, service providers and those of us who collaborate with people who have been labelled to use video and multimedia to tell personal stories. There are no easy answers to these

²³¹ Jane Seale, “The Same but Different: The Use of the Personal Home Page by Adults with Down’s Syndrome as a Tool for Self-Presentation,” *British Journal of Educational Technology* 32, no. 3 (2001): 351.

²³² Jan Walmsley, “Normalisation, Emancipatory Research and Inclusive Research in Learning Disability,” *Disability & Society* 16, no. 2 (2001): 200.

²³³ Nicola Grove and Jen Cavet, “Multimedia Technology for People with Profound and Multiple Impairment,” *An Evaluation of a Mencap Pilot Project Using Multimedia Profiling* (London: PMLD Network, May 2005). http://www.pmldnetwork.org/resources/MMP_Evaluation.doc. 17.

questions. However, each situation can be evaluated based on an assumption of competence, a consideration of the relational impacts of experience-based storytelling and the risks of silencing. What are the benefits for the storyteller in creating an experience-based story?

Although the process aims to empower, there is always a risk of further silencing and oppressing the participant/storytelling by making assumptions about their interests, goals, as well as aspects of their identity, such as their sexual orientation. Conversely, there is also a risk of imposing a self-advocacy story when the person may not be interested in using their video for the purpose of self-advocacy. I know I have had to hold back in video storytelling workshops I have facilitated outside of the self-advocacy movement. I found that many participants wanted to use video to express themselves creatively, to tell funny stories and in some cases to share personal experiences. In the end, I had to recognize that these video stories, although they didn't fit my idea of "videos for social change," could disrupt the categories of intellectual disability or learning disability by positioning the storyteller as an artist.

Storytellers must be engaged in a discussion about the risks of speaking out to help them think about what they choose to say and show in their personal video story. (This is something I had to do myself as I wrote my thesis. The process was the same, I just did not have a support worker assisting me with research, reading and typing.) By focusing on relationships, relational ethics invites storytellers to think about the impact of our stories on ourselves and on others. How do you think so and so would react if he was sitting here with us watching your video? How would you feel about that? Could this hurt

your relationship with this person? Could it hurt him or you? When I struggle with the ethics of disclosure and the possible consequences, I also think about the consequences of silence. I see silencing in the intellectual disability community as a real problem. There is a lot of disclosure happening about people who have been labelled in, for example, “client profiles” or “case histories.” Senehi et al. express one of the dangers of segregation: “One of the ways in which systems of injustice and violence operate most effectively is by disconnecting, disassociating, and dislocating people from their personal and social histories, that is, by disconnecting them from their stories.”²³⁴ At an individual level, the more a person faces serious barriers to communication, the more a connection to his/her own story becomes a matter of survival, especially when close family members have passed on. The person may not be able to say, “Hey, this is who I am, let me be!” Bergum and Dosseter talk about the risks of labels in a hospital context: “Being *with* the person, as a person, is much different than meeting the person as a disease, as a heart, a chart, or a case study. The situation on paper is so flat - - no dance, no rhythm, no music. If the card index [on a hospital bed] does not have room for the qualities of the person, it is easy to fall into the danger of labeling.”²³⁵

In *The Freedom Tour*, people shared their experiences about different types of abuse, many of which were criminal. Gerald's story could not be told nor could Dave's friend living at MDC and many other survivors. On a day-to-day basis however, there is much “pervasive and corrosive”²³⁶ harm that is not considered criminal and may often

²³⁴ Senehi et al., “Dreams of Our Grandmothers: Discovering the Call for Social Justice Through Storytelling,” *Storytelling, Self, Society* 5, no. 2 (2009): 91.

²³⁵ Bergum and Dosseter, *Relational Ethics: The Full Meaning of Respect*. (Hagerstown: University Publishing Group, 2005), 112.

²³⁶ Association for Community Living-Manitoba, “When Bad Things Happen to Women with Intellectual Disabilities,” in *Living the Edges: A Disabled Women's Reader*, ed. Diane Driedger (Toronto: Inanna

“fall under the radar.”²³⁷ From a deficit point of view, people who have been labelled are incompetent. They don't make good decisions and non-labelled people are the competent ones who do. Abuse of power in this context is more difficult to identify since it assumed that the non-labelled staff or parent knows better. Threats to withhold things that people like are common: “Do you want your coffee this morning? Then go have your shower!” and “Stop using that language or you won't be going to the movies tonight.”

I'm at a group home. Five people live here, the house is kept clean, the food is usually good. A staff I have never met before is sitting in the living room watching television. It's 8pm and Jack, who must be in his fifties, walks into the kitchen and grabs an orange. He walks back into the living room. The staff sees the orange and shouts: “Did you ask permission to take that? Put it back! You've already had your snack.” Jack is not happy. I ask the staff: “Why can't he have an orange?” “Oh, if you let him have that, he'll keep asking and asking, he'll never stop.” she responds matter of factly as she turns her head back to the television set.

Who speaks like that to another adult? Why is this so normal for the staff? A video story based on the perspective of the person subject to this type of abuse changes the backdrop against which the situation is viewed. It allows the harm to be noticed as such and not as “the only way to get her to stop swearing or for him to take his shower.” Some of the situations involve very personal and intimate details about a person's life. It may

Publications & Education, 2010), 212.

²³⁷ Ibid.

not always be possible nor appropriate to discuss certain situations without compromising the storyteller's right to privacy. However, this pervasive and corrosive abuse identified in a study by Community Living-Manitoba must be addressed: it is a serious issue. This is where fiction can help us as storytellers, self-advocates and filmmakers. I will discuss the potential for fiction in a bit, but first I would like to say a few words about empowerment.

When I first began my work with People First, I had read much about the empowerment that happens as a result of using media for self-representation. However, I never felt comfortable with the thought that I was empowering people. I am not denying that it was flattering to hear people say that I was giving people a voice and other such things. Something about it didn't feel right. It gave me too much importance, too much power. From my experience of working with Valerie, Dave, Susie, Mark and Kevin, I learned that empowerment was mutual. To get the project done, I needed them just as much as they needed me. I was empowered by People First members' stories to push forward with the project of making the documentary collaboratively: I took my strength and my determination from working very closely with the co-directors. Rather than empowering them through the collaborative process, I saw my role as “fostering space for persons to find and take hold of the personal inner power that is already present.”²³⁸ It has catapulted Dave from being a local People First member to becoming a member of the Joint National Task Force on Deinstitutionalization. Dave was always there with his inner strength. The process of working collaboratively on a film simply helped to shine a light on it so that more people might notice.

²³⁸ Bergum and Dosseter, *Relational Ethics: The Full Meaning of Respect* (Hagerstown: University Publishing Group, 2005), 92.

Another way of thinking about empowerment which I feel acknowledges competence, and is based on mutuality, is collective empowerment. When I read about Barrios and Gloria Anzaldúa's experience-based writing and "agency as an achievement . . . developed only with constant and collective work,"²³⁹ I realized that I preferred to think about empowerment on a collective basis rather than an individual basis. Without the existence of the supportive community found in the self-advocacy movement, the practice of sharing life stories would be very difficult. Stone-Mediatore talks about the risky nature of writing from experience: "For both (Barrios and Anzaldúa), such narrative work is empowering as well as treacherous and is possible only with a supportive community."²⁴⁰ The supportive community is key to this type of personal storytelling: the People First movement represents such a supportive community for self-advocates and allies. How many times did I feel discouraged or have doubts about the work I was doing? Many. All I had to do was to talk with the co-directors or to meet with them to feel my doubts dissipate and my courage and energy come back to me. The mutuality of empowerment has to be openly acknowledged. Besides, Arendt provides a very clear definition of power as "the human ability not just to act but to act in concert. Power is never the property of an individual; it belongs to a group and remains in existence only so long as the group keeps together."²⁴¹ As a non-labelled person working in collaboration with people who have been labelled, it is important that I make this clear. As a result of being immersed in the People First movement, I was able to practice the fearlessness of being myself and doing what I believe is right. A collaborative approach

²³⁹ Shari Stone-Mediatore, *Reading Across Borders: Storytelling and Knowledges of Resistance* (New York: Palgrave-MacMillan, 2003), 150.

²⁴⁰ Ibid, 152.

²⁴¹ Hannah Arendt, *On Violence* (New York: Harcourt Publishing, 1970), 44.

assumes competence, is mutually empowering and invites a practice of mutual respect.

Bergum and Dosseter ask: “Could it be that the full meaning of respect is this concept of mutuality? In mutuality we need to be present with the other with both heart and mind. It is not easy to practice the value of mutual respect in day-to-day life.”²⁴² Although it is difficult, I can practice being present in heart and mind to reduce the harm I may inflict on the people I meet, work with, and those who I live with.

Filmmaker as Advocate: Recognizing Some of the Pitfalls

Walmsley points out one of the risks of positioning oneself as an advocate while working inclusively:

Researchers [or filmmakers in my case] working within an inclusive paradigm are, like the Booths, almost invariably highly committed to improving the lot of people with learning difficulties. Yet whilst it is important that negative myths about people with learning difficulties are challenged through research [or video stories], the result can be a somewhat uniform representation of people with admirable human qualities struggling to make the most of difficult lives. I have nothing against this, but it may be replacing one stereotype with another.²⁴³

This danger of replacing one stereotype with another is something I have been thinking about. Did I encourage a flat representation of people's experiences? Whether we have been labelled or not, we have all been affected by the same sexist, racist and ableist ideas that permeate society. It is our job as activists, storytellers, self-advocates, researchers and filmmakers to become acquainted with our prejudices and assumptions. Although I

²⁴² Vangie Bergum and John Dosseter, *Relational Ethics: The Full Meaning of Respect* (Hagerstown: University Publishing Group, 2005), 81.

²⁴³ Jan Walmsley, “Normalisation, Emancipatory Research and Inclusive Research in Learning Disability,” *Disability & Society* 16, no. 2 (2001): 201.

strived to strike a balance between women and men and to include non-verbal people who had survived institutions as well as People First members participating in *Label Free Zone* video workshops, I didn't push my thinking much beyond that. Again, I was thinking in terms of balancing views and adding “drops of truth” instead of searching for the particular knowledge that these differently-situated survivors and People First members could contribute to a furthering an understanding of the experience of institutionalization and living in the community. The perspective of racialized self-advocates, like Jackie Downer, remind all of us that people who have been labelled, regardless of living marginalized lives, struggle with the same issues as the rest of society in terms of inclusion and power:

Downer makes the case for challenging the hegemony of white and relatively able men in the self-advocacy movement, arguing forcefully that ways need to be found to include people with more severe and profound impairments. Although the diversity of people with learning difficulties has been celebrated, there's been little examination of power relationships within the movement.²⁴⁴

This observation is important to keep in mind if experience-based video stories are to inform us about the great diversity of realities experienced by labelled people, including people labelled as having profound intellectual disabilities, women, native people and people who have been racialized. As a member of a marginalized group of people, we are not immune from making wrongful assumptions about people who are different from us. Minority Francophone communities in Canada exclude members from other marginalized positions and lose many opportunities to ensure the vitality and pertinence of their (our)

²⁴⁴ Ibid, 198.

community. By positioning myself as an advocate, was I able to ask difficult questions about sexism, racism, heterosexism and ablism within the movement? Was it my role? To be honest I don't remember talking about these issues, ever. Could I, as a filmmaker and facilitator encourage storytellers to speak not only from their perspective as people who have been labelled but from other aspects of their identity such as gender, sexual orientation, skin colour and other physical characteristics? Could I ask them to think about these other aspects of identify that are so often ignored, not just within the self-advocacy movement, but in most communities? Stories from marginal standpoints from within the intellectual disability community are making their way to the public via the Internet. *Richard's Story* is a short video by SocialCareTV about a gay man with a learning disability who talks about his desire to have a relationship.²⁴⁵ Stories like this one contribute to unsettle and complicate the category of intellectual disability by focusing on aspects of identify such as gender and sexual orientation. It helps to shatter the monolithic portrait of “an intellectually disabled man.”

We must continue, as Zizek suggested, to “Dare to disturb the underground of the unspoken underpinnings of our everyday lives.”²⁴⁶ Storytelling based on lived experiences from the margins remains, for me, an accessible and creative way to nourish this disturbance. Zizek claimed that “This obscene underground, the unconscious terrain of habits, is what is really difficult to change”²⁴⁷ He was speaking in this case about the Catholic Church as an institution that “systematically creates conditions for such crimes [pedophilia]”²⁴⁸ However, he could be talking about the institutions created for people

²⁴⁵ To listen to his story, go to: <http://www.youtube.com/watch?v=lyR8RFwAGhE>.

²⁴⁶ Slavoj Zizek, *Violence: Six Sideways Reflections*. New York: Picador, 2008), 168.

²⁴⁷ Ibid.

²⁴⁸ Ibid.

with so-called intellectual disabilities. As Pat Worth, one of the founders of the People First movement in Canada, said, “An institution is not just a place, it is the way people think.”²⁴⁹ This way of thinking, that is based on assumptions of incompetence, has not disappeared along with the institutions that have closed down. It will take continuous collective effort to destabilize the unconscious terrain of habits where we are so easily lured to a deficit-based understanding of intellectual disability. Just as practicing mutual respect is very difficult to practice on a day-to-day basis, so is assuming competence in others. I have worked to assume competence in all people who have been labelled with an intellectual disability; I make it my starting point as a person working collaboratively with them to tell personal stories. I have yet to apply this approach to non-labelled professionals working within the system of service provision. I still have a way to go but go I must if I am to be useful in any way to furthering the interests of people who have been labelled with an intellectual disability.

Working Through (and with) the Anger

Although I sometimes worried about the impression *The Freedom Tour* documentary made on people and the ugly truths it expressed, I also felt that the anger was justified and that it had (has) to be expressed and acknowledged as valid. *The Freedom Tour* documentary was a public expression of anger at what has happened and continues to happen to people who have been labelled, unacknowledged by governments and by the general population. It is normal to be angry about that. I am still angry about

²⁴⁹ Worth, Pat, “Dare to Dream,” published on Inclusion Network.
<http://www.inclusion.com/respatworth.html>.

the horrible neglect and abuses people have endured and continue to endure in all sizes of institutions. Before I can move beyond anger, recognition is essential. It is important for me to publicly recognize the damage caused to people who have been labelled with an intellectual disability and their families. Expressions of anger and acts of resistance in the institutions were met with punishment of all kinds, from losing “privileges” to days of isolation and deprivation in the so-called QT (Quiet Time) or Time Out rooms. When people who have been labelled with an intellectual disability get angry, it can be labelled as undesirable or difficult behaviour, it can be dismissed as insignificant or childish. Instead of trying to understand where the anger and frustration was coming from, all efforts go into suppressing the expression of anger. People who have been labelled with an intellectual disability have the right to be angry; especially when I think of all the attempts to control and modify their behaviour and about the publicly-funded institutions like MDC defended by medical professionals, public servants and families as appropriate options based on the concept of a continuum of care. I still get angry when I see that as recently as 1990, local businesses in Portage la Prairie joined in the celebration of MDC's centenary by purchasing ads in the local newspaper: “Caring People like yourselves, both past and present, help to make life more meaningful” and “A great past . . . a great future!!” by the Toronto Dominion Bank, “Your continuing progress benefits us all. Thank you!!” and “Congratulations!! We are proud to have you as part of our city.”²⁵⁰

I don't think that my anger will subside until there is public acknowledgement and a willingness to talk with people who have been labelled with an intellectual disability based on an assumption of competence. While I acknowledge my anger, I also realize that

²⁵⁰ *The Portage la Prairie Daily Graphic: The Central Manitoba Herald Leader Press*, July 10, 1990, 13.

I must work from an assumption that all people, not just people who have been labelled, are competent and therefore capable of enlarged thought as Stone-Mediatore says about experience-based stories. I must work through my anger if I am to assist people who have been labelled to create video stories capable of sparking a much needed dialogue among equals. As bell hooks puts it in *Teaching to Transgress* perhaps it is about openly acknowledging the anger and the history precedes relationships between labelled and non-labelled people. Her advice to black women resonated with me:

black women need to explore our collective attachment to rage and hostility towards white women. It may be necessary for us to have spaces where some of that repressed anger and hostility can be openly expressed so that we can trace its roots, understand it, and examine possibilities for transforming internalized anger into constructive, self-affirming energy we can use effectively to resist white female domination and forge meaningful ties with white female allies.²⁵¹

As much as anger has a place and needs to be expressed, I must be mindful about when and where it is expressed. It is difficult sometimes to know where to direct this anger since, as Arendt's explanation of rule by bureaucracy illustrates "it is this state of affairs, making it impossible to localize responsibility and to identify the enemy."²⁵² Being shuffled from one department to the next and one level of service to the next results in feelings of anger, rage and sometimes hopelessness. Support workers, parents, teachers, artists, siblings are all potential allies as long as the history of oppression of people with so-called intellectual disabilities is openly acknowledged as well as the fallacies upon which it has been based. More connections and stronger ties are needed to build up the

²⁵¹ bell hooks, *Teaching to Transgress: Education as the Practice of Freedom* (New York: Routledge, 1993), 109.

²⁵² Hannah Arendt, *On Violence* (New York: Harcourt Publishing, 1970), 39.

power that has the potential to disrupt the harmful relationship of domination. As Meadours, a People First member from Tulsa Oklahoma, said: we “need to work together – not against each other.”²⁵³

By adopting a mutually respectful approach with all potential allies, I have a chance, as an activist and community filmmaker to affect the kind of change I seek. Bergum and Dosseter propose that: “To gain understanding we can walk beside others and talk with them. It means we need to talk together about serious issues.”²⁵⁴ We must pull assumptions about labelled and non-labelled people out from under and put them up for open discussion. There has to be a willingness on behalf of non-labelled people to acknowledge the advantages of allowing these assumptions to go unchecked. “It is time for us to create new models for interaction that take us beyond the servant-served encounter.”²⁵⁵ An effort must be made on behalf of self-advocates, allies and family members, like myself, to not give into cynicism and to not give up on building connections across abilities. Otherwise, hooks warns us, we become complicit in maintaining the status quo.

Looking to Fiction to Tell Experience-Based Stories

I mentioned earlier that fiction might be of help to bring situations of systemic and symbolic violence to forefront of our thoughts. Fictional stories based on lived-experience might reduce the risks for people who have been labelled when disclosing traumatic

²⁵³ James Meadours, “James Meadours,” in *A Celebration of Stories*, People First of Canada and People First of Ontario, (North York: Copywell, 1993): 33.

²⁵⁴ Bergum and Dosseter, *Relational Ethics: The Full Meaning of Respect* (Hagerstown: University Publishing Group, 2005), 80.

²⁵⁵ bell hooks, *Teaching to Transgress: Education as the Practice of Freedom*. (New York: Routledge, 1993), 108.

events like situations of abuse. According to Hannah Arendt storytelling “reveals meaning without committing the error of defining it, . . . it brings about consent and reconciliation with things as they really are.”²⁵⁶ I will share a few thoughts about this using a recent short film as an example. Willowbrook,²⁵⁷ a short film presented as “based on true events” tells the story about a new intern at Willowbrook, who was shocked to learn that inmates are administered hepatitis with parents' consent. After witnessing an encounter between Dr. Harowitz and a non-verbal “patient's” mother, the intern was concerned for her boy Brian's safety. He called the mother at home to warn her about the hepatitis shot if she signed the consent form. As he was preparing to leave that night after his shift, he walked past the boy's room. Brian was sitting in his chair staring out the window.

“How did *you* get out of bed?” asked the intern.

“I flew,” the boy answered with a hint of sarcasm.

“What?” asked the intern in disbelief.

“I'm kidding,”²⁵⁸ the intern reassured him.

What followed was a short conversation, which was a figment of the intern's imagination. The dialogue allowed the audience to enter the subjective position of the boy who was incarcerated at Willowbrook. Hearing Brian talk was very powerful since it assumed that the boy was a thinking subject. The filmmaker made a non-talking person “talk” to invite the audience to try to imagine being in this boy's situation. I found it very effective but I also had questions such as; Who imagined what a non-verbal person might say or might think in such a situation? Was this the only way to represent the boy as a competent and

²⁵⁶ Hannah Arendt, *Men in Dark Times* (New York: 1973, Harcourt Brace & Company), 107.

²⁵⁷ *Willowbrook*, Dir. Ross Cohen, 2012, DVD.

²⁵⁸ *Willowbrook*, Dir. Ross Cohen, 2012, DVD.

thinking subject? How could a non-verbal person's subjectivity be represented without recourse to spoken words? How could camera angles, movements and framing be used to represent a person's perspective without putting words in his/her mouth? Collaborative approaches with people who have been labelled to tell stories based on personal experiences can benefit from experimenting with fictional or creative non-fiction²⁵⁹ (as Kelly used in her video story) and also from poetry as Burton Blatt used to write his book *Revolt of the Idiots: A Story*, as forms of representation. Blatt wrote about his experience of writing about institutions: "Didn't she [Pennington] say that artists distort reality to create reality? What does one do when reality doesn't need artistic distortion, when distortion is part of the natural fabric, when distortion is reality? Is that special reality, then, a creation of art or a result of madness?"²⁶⁰

The more I think about all the stories told in the context of making *The Freedom Tour* and the *Label Free Zone*, the more I am drawn to the idea of using fiction and poetry based on lived-experience as a way of telling them. For me, this would mean collaboratively writing scripts with small groups of people who have been labelled. People who are labelled, as Stone-Mediatore explained, experience daily the hidden costs of social contradictions, shift in and out of cultural worlds, engage in activities that defy the dualisms and exclusions of their label and resist social relations that ruling beliefs present as "natural"²⁶¹ just by trying to live their lives. There is endless material to illustrate the issues I have touched upon in this thesis: power, gatekeeping, consent,

²⁵⁹ An approach used by Michael V. Angrosino adopted to write *Opportunity House* (1998). It is disappointing though that the author uses the label "mental retardation" in such a recent publication.

²⁶⁰ Burton Blatt, *Revolt of the Idiots: A Story* (Glenridge: Exceptional Press, 1976), 23.

²⁶¹ Shari Stone-Mediatore, *Reading Across Borders: Storytelling and Knowledges of Resistance* (New York: Palgrave-MacMillan, 2003), 184.

silencing, respect, labels, control, competence, exclusion, bureaucracy, institutionalization, mutuality, collaboration and so on. These scripts, like the work I did with People First members, would be based on lived experiences of people who have been labelled. Instead of a realist style of documentary, the creation of fictitious stories would permit the blending of anecdotes, the creative representation of a variety of subjectivities. These scripts could be read by groups of parents, by medical students or professionals, by support workers and social workers. By listening to a reading of the script or by reading the lines of different characters, they could be invited to react and to respond to these scripts. Instead of intervention theatre (as the Theatre of the Oppressed developed by Augusto Boal), could there be intervention scriptwriting? Could this sort of collective narrative approach²⁶² represent a non-threatening approach to explore “our unconscious terrain of habits?”²⁶³ Who would decide when the script is ready for production? I still have many questions but I think this avenue is worth exploring. This approach would give people more freedom to tell their stories since the consequences of disclosure, as Zingaro²⁶⁴ calls them, would be minimized in a collective fictional narrative where individual people are not put under the spotlight but characters are created and interpreted by artists who have been labelled with an intellectual disability.

²⁶² Collective narrative approaches have been widely used by the Dulwich Centre in Australia and have been developed so that “individuals and communities who are going through hard times can make contributions to the lives of others who are going through similar difficulties” David Denborough, 2008, 4. Collective narrative practice is aimed at non-professionals.

²⁶³ Žižek, Slavoj (2008): 168.

²⁶⁴ See Linde Zingaro, *Speaking out: Storytelling for social change* (Walnut Creek: Left Coast Press, INC., 2009).

CONCLUSION: Learning From Our Stories

Although I went into collaboratively making videos with people who have been labelled with an intellectual disability inspired by participatory video projects such as the NFB's *Challenge for Change* program, *ThisAbility*²⁶⁵ Media Project, none of the articles I managed to find gave me an in-depth and detailed description about working collaboratively. I would have greatly benefitted from a first-hand description of these projects by the filmmakers or facilitators but none were available at the time. That was my main motivation for writing about my experiences. Another equally important motivation for writing was to try to understand my motivations, to reflect on my role and to uncover some of my assumptions as they related to collaborative approaches of working with labelled people to make experience-based videos.

I continue to appreciate the guidance of Walmsley and Johnson's principles of inclusive research, with the addition of the idea of assuming competence. Stone-Mediatore's theory of storytelling has helped me to explain the epistemic value of experience-based stories better while Zizek's distinction between subjective and objective violence has reminded me to stay focused onto the more invisible systemic and symbolic violence that manifests in our everyday interactions. Zizek invited us to not get caught up in with the subjective violence that is a result of social inequalities. How can these ideas help us to think about such emotionally charged social issues such as prenatal screening for chromosomal variance? How can labelled and non-labelled people talk openly about these issues without losing our ability to think clearly and without blame? Can

²⁶⁵ See Lorna Boschman, "Applying photovoice methods to community based media," July 2006. <http://www.sfu.ca/~lboschman/july06/applying-photovoice-July10.html>.

experience-based video storytelling help us widen our view to see beyond individual choices and problems? I hope so. Video storytelling is the same for people who have been labelled, but different because of the need for human support and the assumptions made about their capabilities. There is every sign that the use of video, photography and multimedia by people who have been labelled is increasing. As these experience-based stories become more available, I look forward to discovering new and creative ways to engage with, and facilitate the production of these stories, as a “way to examine critically the narrative paradigms and discursive norms that structure 'objective' knowledge and are presupposed by established cultural institutions.”²⁶⁶

In other words, I will advocate for the recognition of the legitimate value of personal stories told in plain language, using pictures, moving images, drawings whatever it takes, as a way of learning from the experiences of people who have been labelled. I will also argue that this recognition will go a long way to reducing the symbolic violence enacted upon labelled people by changing the zero-ground level against which things are judged as “normal.” Perhaps then, we will finally be able to see beyond labels and identify the very real social and cultural institutions that continue to classify, segregate and underserve labelled people.

“C'est une histoire de famille”

I remember the reaction of a former colleague of mine when I told her that I was thinking of taking the Disability Studies program at the University of Manitoba “Don't

²⁶⁶ Shari Stone-Mediatore, *Reading Across Borders: Storytelling and Knowledges of Resistance*. New York: Palgrave-MacMillan, 2003), 190.

choose something because it's important to your family.” I didn't understand what she meant by that and I still don't. For me, professional and personal are intimately related and I have no desire to change that. I have made a choice to work with people who have been labelled with an intellectual disability, because I care what happens to these people. I am not going anywhere, I plan to continue my work until nobody has any use for my skills. The next time I make videos, or write about my work it will probably be in French as I try to reach my own francophone community here in Ontario. From working with a national organization, on national projects, I am now ready to use my energy to try to create positive social change for Franco-Ontarians labelled with an intellectual disability. It reminds what my boss had said to me during my coop placement during my undergraduate program: “You need to know what your goal is then to keep working at it, never losing sight of what it is you are trying to achieve”. Nothing more and nothing less than contributing to a redefinition of intellectual disability.

Disability has defined who I am. It has not confined me as a sibling unlike the predictions found in research stemming from a medical model. Alongside other aspects of my identity, it has nurtured my desire for social justice as well as my curiosity about human behaviour. Those are the main side-effects for me. When I was little and people asked me what was wrong with my brother, I enjoyed impressing people by saying “The doctors say he has hypokalemic periodic paralysis.” Later, when I was thirteen, I thought I should become a psychiatrist to understand how the brain works so I could help my brother. Now, I just want to tell people that there isn't anything wrong with him or any other person who has been labelled with an intellectual disability, let's just try to figure

out how to live together. “Bergum (2004, p. 491) captures the significance of relationships in her explanation that ‘we can only live well autonomously if we live well together’ – the notion that moral good and happiness is rooted in our relationships with others.”²⁶⁷

Epilogue: A Conversation with Valerie

While Valerie was visiting me in Ottawa, during an extended stay thanks to her participation in the End Exclusion Conference, we sat down to talk about some of the stories I've written about our experience of making *The Freedom Tour*. I asked her, “Remember when we tried to interview Dave's friend in the institution?” “Yeah, and the Public Trustee was playing games with us because first they said no, then they said yes and then they said no again,” said Valerie. Yes and that was just the day before we were ready to interview him. It's strange because in the end, I had to agree with the Public Trustee, but I suspect that it wasn't for the same reasons. Had they really been concerned for his well-being, he wouldn't have been living in a place where interviewing him might put him at risk of staff reacting negatively. Dave's friend passed away just before *The Freedom Tour* was screened. We never got to take a picture of him or record his gentle voice but we did dedicate the film to him.

Valerie and I sat down in one of the bedrooms upstairs, away from everyone, and took some time to talk about what I had written in this paper. I recorded our conversation. It sounded quite nice. It's too bad I have to destroy this interview after I've

²⁶⁷ Vangie Bergum, (2004), p. 491 cited by Hannah MacDonald in “Relational Ethics and Advocacy in Nursing : A literature Review” in *Journal of Advanced Nursing*, Vol. 57, Issue 2, p” 119-126.

defended my thesis!

“So Valerie, you remember when you worked on your video self-portrait when we were at Video Pool with Erika?”

“Yeah, I was flying up in the sky when we had this blue background.”

“I know that was a while ago, but do you remember how you felt telling that story, you know about when you were a kid and about the Public Trustee?”

“Mmmm, well I know that all that information has to get out there. So that other people who had the same experiences as I had.”

“But was it difficult, did you feel shy?”

“Well, humm, I felt I guess OK about doing that story. Well mixed reactions because that time when we did go out to Poplar Point and stuff, I felt it was hard, difficult, the weather was kinda crappy. Yeah, it was difficult because I think it was ten years after my late mum had passed away so the memories were coming back again.”

“So it brought back a lot of memories... ”

“And about when I went to Portage la Prairie and had to go to that segregated school.”

“And I drove around and Erika filmed as you showed us where you used to live and your old school. When you went back home, how did you feel about it?” I asked.

“Uh, I felt OK because I felt the story needs to be told,” Valerie responded.

“Cause sometimes, if it brings back bad memories it can, a person can feel sad so I wonder about that because we worked on this project and a lot of people talked about abuse and other difficult things.”

“Yeah, abuse that's happened in our lives.”

“and we didn't, hum, have any counselors or anything,” I continued.

“No.”

“to help people in case they felt really bad and I wonder, maybe we should have, you know?”

“Counsellors that come with you?” asked Valerie.

“No, they wouldn't come with us to the interviews. We could have volunteers to call people after the interview to see how they're doing, to ask them if there's anything they would like to talk about or if they think they might need some help finding a counselor.”

“Well, I figure that if they really want to they should be able to be out there unless they're unfortunately under the public trustee which is another story and which I was under for a while and I had to fight to get off that and overcome.”

“So like, have you ever felt that after sharing stories about some difficult things that have happened to you, has it made you feel worse?” I asked.

“I think before we did make the movie, I think I felt worse, but then sometimes our mind changes, you know?”

“So how did your mind change?”

“Humm, I think as we get older, we forget about some of those things, and I guess my Christianity and I have some positive people that I can phone and before when I was living in that group home I didn't even know that I had any rights because I was under the public trustee then too,” said Valerie. “and I was happy that I was able to have the time and the commitment to help plan everything.”

“So when you see yourself up there on the big screen talking about the public trustee and telling your story, how do you feel?”

“Well, um, I feel that personal stories need to get out there for other people to tell their personal stories too.” “And why do you think it's good for other people?”

“If they're in the same type of situation and maybe they would come and talk to me to see what I went through too.”

“To see how you got off the public trustee?”

“Yeah, cause of experience and when I had the privilege of going to Israel and when I was over there, I thought, wow, if I can be across the world then I think I can get off this public trustee too. I had the determination, it's very difficult to get off once you're on,” and when Valerie says this, I'm reminded of something Dave says in *The Freedom Tour* to his friend Wayne about their time at MDC, “It's easy to get in but it's hard to get out.”

Bibliography

- Alberta Association for Community Living. *Hear My Voice: Stories Told by Albertans with Developmental Disabilities Who Were Once Institutionalized*. Saskatoon: Copestone Writing and Illustrating, 2006.
- Arendt, Hannah. *On Violence*. New York: Harcourt Publishing, 1970.
- _____. *Men in Dark Times*. New York: Harcourt Brace Jovanovich, 1968.
- Aspis, Simone. "Researching Our History: Who Is In Charge?" in *Crossing Boundaries: Change and Continuity in the History of Learning Disabilities*, edited by Lindsay Brigham, Dorothy Atkinson, Mark Jackson, Sheena Rolph and Jan Walmsley, 1-5. Kidderminster: BILD Publications, 2000.
- Association for Community Living-Manitoba. *Proposal Regarding the Manitoba Developmental Centre*. Revised February 21, 2009.
- _____. "When Bad Things Happen to Women with intellectual Disabilities" in *Living the Edges: A Disabled Women's Reader*, edited by Diane Driedger. 206-220. Toronto: Inanna Publications & Education, 2010.
- Atkinson, Dorothy, Mark Jackson and Jan Walmsley. *Forgotten Lives: Exploring the History of Learning Disability*. Kidderminster: BILD Publications, 2003.
- Bergum, Vangie and John Dossetor. *Relational Ethics: The Full Meaning of Respect*. Hagerstown: University Publishing Group, 2005.
- Bérubé, Michael. "Autobiography as Performative Utterance." *American Quarterly* 52, no. 2 (June 2000): 339-343.

- Biressi, Anita and Heather Nunn. *Reality TV: Realism and Revelation*. London: Wallflower Press, 2005.
- Blatt, Burton, *Revolt of the Idiots: A Story*. Glenridge: Exceptional Press, 1976.
- Blatt, Burton and Fred Kaplan. *Christmas in Purgatory: A Photographic Essay on Mental Retardation*. Boston: Allyn & Bacon, 1966.
- Blatt, Burton, Andrejs Ozolins, and Joe McNally. *The Family Papers: A Return to Purgatory*. New York: longman, Inc., 1979.
- Blumer, Herbert. "Society as Symbolic Interaction". In *Symbolic Interaction: An Introduction in Social Psychology*, edited by Nancy Herman and Larry Reynolds, 263-266. Dix Hills: General Hall, Inc., 1994.
- Bogdan, Robert and Steven Taylor. (1989): "Relationships with Severely Disabled People: The Social Construction of Humanness." *Social Problems*, vol. 36, iss. 2, p. 135-147.
- Booth, Timothy and Wendy Booth. "*Parenting Under Pressure: Mothers and Fathers with Learning Difficulties*." Buckingham, Open University Press, 1994.
- Boschman, Lorna: "Applying Photovoice Methods to Community Based Media." July 2006. <http://www.sfu.ca/~lboschman/july06/applying-photovoice-July10.html>.
- Boulanger, Josée, Susie Wieszmann and Valerie Wolbert, "*The Freedom Tour* documentary: An Experiment in Inclusive Filmmaking." In *Living the Edges: A Disabled Women's Reader*, edited by Diane Driedger, 305-322. Toronto: Inanna Publications & Education, 2010.
- Bourdieu, Pierre, et al. *The Weight of the World: Social Suffering in Contemporary*

- Society*. Stanford: Stanford University Press, 1993.
- Burnett, Ron. "Video: The politics of Culture and Community." In *Challenge for Change: Activist Documentary at the National Film Board of Canada*, edited by Thomas Waugh, Michael Brendan Baker and Ezra Winton, 61-65. Montreal & Kingston: McGill-Queen's University Press, 2010.
- Candle of Hope*. Canadian Association for Community Living and People First of Canada, 2004. Videocassette.
- Charlton, James. *Nothing About Us, Without Us: Disability Oppression and Empowerment*. London: University of California Press, 1998.
- Close, Chuck. "Forget Inspiration – Just Trust the Process." *doug toft*. (September 19, 2011) <http://dougtoft.net/2011/09/19/forget-inspiration%E2%80%94just-trust-the-process>.
- Community Living Ontario, "Inclusive Education," "Advocacy, Rights & the Law," <http://www.communitylivingontario.ca/fr/node/1397>.
- Couser, Thomas G. "The empire of the "Normal": A forum on disability and self-representation: Introduction." *American Quarterly* 52, no. 2 (June 2000): 305-310. Project Muse.
- Danny and Nicky*. National Film Board of Canada, 1969. Videocassette.
- de Cherisey, Pozzo di Borgo, Philippe and Jean Vanier. *Tous intouchables?*, Bayard, Montrouge Cedex, 2012.
- Denborough, David. *Collective Narrative Practice: Responding to Individuals, Groups, and Communities who have Experienced Trauma*. Adelaide: Dulwich Centre

Publications, 2008.

Disabling Imagery? Short Films and Film Clips Exploring Disability Issues, British Film Institute Education, 2003, DVD.

Dillon, Robin. "Respect and Care: Toward Moral Integration." In *Respect for the Elderly: Implications for Human Service Providers*, edited by Kyu-taik Sung and Bum Jung Kim, 23-44. Lanham: University Press of America, 2009.

Douglas College in British Columbia, "Cognitive Disability."

<http://www.douglas.bc.ca/services/centre-for-disabilities/documentation/cognitive.html>.

Duncan, Margot. "Autoethnography: Critical Appreciation of an Emerging Art." *International Journal of Qualitative Methods* 3, no. 4 (2004).

http://www.ualberta.ca/~iiqm/backissues/3_4/html/duncan.html.

Education. "Breaking Barriers: Campus Life Student Exposes the Hurt of Being Excluded." (March 29, 2012).

<http://blogs.cc.umanitoba.ca/education/2012/03/29/breaking-barriers>.

Ellis, Carolyn. *Revision: Autoethnographic Reflections on Life and Work*. Walnut Creek: Left Coast Press Inc., 2009.

Ellis, Carolyn, Tony E. Adams & Arthur P. Bochner, "Autoethnography: An Overview," *Forum Qualitative Research* 12, no. 1, art. 10 (January 2011).

<http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095>.

Eternal Children: The Problem of the Retarded Child. National Film Board of Canada, 1959. Videocassette.

- Forest, Heather. "Artful Leadership for Creating Positive Social Change: Reflections on an Arts-Based Autoethnography." *Storytelling, Self, Society* 5, no. 2 (2009): 72–89.
- Garland-Thomson, Rosemarie, "The Politics of Staring: Visual Rhetorics of Disability in Popular Photography." In *Disability Studies: Enabling the Humanities*, edited by Sharon L. Snyder and Brenda Jo Brueggemann and Rosemarie Garland-Thomson, 56-75. New York: Modern Language Association of America 2002.
- Garland-Thomson Rosemarie. *Staring: How We Look*. Oxford University Press, 2009.
- Goddard, Stephen. "Anecdotes and Antidotes – Stories as Balms, Storytelling as Healing," *Art and Pain*, issue. 4 (Winter 2003).
http://www.doubledialogues.com/archive/issue_four/goddard.htm.
- Goffman, Erving. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Doubleday Anchor, 1961.
- Goodley, Dan. "Tales of Hidden Lives: A Critical Examination of Life History Research with People Who Have Learning Difficulties." *Disability and Society* 11, no. 3 (1996): 333-348.
- _____. *Self-Advocacy in the Lives of People with Learning Difficulties*. Maidenhead: Open University Press, 2000.
- Goodley, Dan and Michelle Moore. "Doing Disability Research: Activist Lives and the Academy." *Disability and Society* 15, no. 6 (2000): 861-882.
- Goodley, Dan. "'Learning Difficulties', the Social Model of Disability and Impairment: Challenging Epistemologies," *Disability & Society* 16, no. 2 (2001): 207–231.

- Goodley, Dan, Griet Roets and Geert Van Hove. "Narrative in a Nutshell: Sharing Hopes, Fears, and Dreams with Self-advocates." *Intellectual and Developmental Disabilities* 45, no. 5 (2007): 323-334.
- Grierson, John. "Memo to Michelle About Decentralizing the Means of Production (1972)." In *Challenge for Change: Activist Documentary at the National Film Board of Canada*, edited by Thomas Waugh, Michael Brendan Baker and Ezra Winton, 61-65. Montreal & Kingston: McGill-Queen's University Press, 2010.
- Griffith, Morwenna. *Action for Social Justice in Education: Fairly Different*. Maidenhead: Open University Press, 2003.
- Grove, Nicola and Jen Cavet. "Multimedia Technology for People with Profound and Multiple Impairment." An Evaluation of a Mencap Pilot Project Using Multimedia Profiling (London: PMLD Network, May 2005).
http://www.pmldnetwork.org/resources/MMP_Evaluation.doc.
- Hansen, Nancy E., Heidi L. Janz and Dick J. Sobsey. "21st Century Eugenics?" *The Lancet* 372, (December 2008): 104-107.
- hooks, bell. *Teaching to Transgress: Education as the Practice of Freedom*. New York: Routledge, 1993.
- How's Your News?* Director: Arthur Bradford, 1999. DVD.
- Ignani, Esther. "The Freedom Tour." *Journal on Developmental Disabilities* 15, no. 1, (2009): 67-70.
- "Images On Screen Promote Aboriginal Cliches," *Ottawa Citizen Online*, Wednesday, February 12, 1997.

- Institutionwatch.ca. "Declaration of Support for Community Living." Canadian Association for Community Living and People First of Canada.
<http://www.institutionwatch.ca>.
- Johnson, Kelley and Traustadóttir Rannveig. (2000) *Women with Intellectual Disabilities: Finding a Place in the World*. London: Jessica Kinglsey Publishers Ltd., 2000.
- Jordan, A., "Ontario: Canada: Reversing the gains made in special education." Paper presented at the International Special Education Congress, University of Manchester, Manchester, United Kingdom, July 2000.
- Juhasz, Alexandra. *AIDS TV: Identity, Community, and Alternative Video*. Durham: Duke University Press, 1995.
- Keys of Our Own*, Canadian Association for Community Living, 1993. Videocassette.
- Leavy, Patricia, *Method Meets Art: Arts-based Research Practice*. New York: The Guilford Press, 2009.
- Mansfield C, Hopfer S, Marteau TM., "Termination Rates After Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: a Systematic Literature Review. European Concerted Action: DADA (Decision-making After the Diagnosis of a Fetal Abnormality)." *Prenatal Diagnosis* 19 (1999): 808–12. Cited by Brian G. Skotko in "With New Prenatal Testing, Will Babies With Down Syndrome Disappear?" *Archives of Disease in Childhood* 94, no 11 (November 2009).
- McGraw, Lori A. and Alexis J. Walker. "Meanings of Sisterhood and Developmental Disability: Narratives From White Nondisabled Sisters." *Journal of Family Issues*

- 28, no. 4 (April 2007): 474-500.
- McIlroy, Anne. "Doomed from Birth to Death." *Globe and Mail*, Saturday, May 5, 2007, Front page, Prairie Edition.
- Meadours, James. "James Meadours." In *A Celebration of Stories*, People First of Canada and People First of Ontario, 32-33. North York: Copywell, 1993.
- Melberg, Schwier, Karin. *Speakeasy: People with Mental Handicaps Talk About Their Lives in Institutions and in the Community*. Austin: Pro-ed, Inc., 1990.
- Metzel, Deborah S. and Pamela M. Walker. "The Illusion of Inclusion: Geographies of the Lives of People with Developmental Disabilities in the United States." *Disability Studies Quarterly* 21, no. 4 (Fall 2001):114-128.
- Ministry of Community and Social Services. "Ontario Closes Institutions for People With a Developmental Disability: McGuinty Government Ends The Era Of Institutionalization," News Release, March 31, 2009 2:30 pm.
<http://news.ontario.ca/mcss/en/2009/03/ontario-closes-institutions-for-people-with-a-developmental-disability.html>.
- Moen, Torill. "Reflections on the Narrative Research Approach." *International Journal of Qualitative Methods* 5, no. 4, (December 2006): 1-11.
- Morgan, Charlotte. "A Brief History of Special Education." *EFTO Voice* 7, no. 2 (Winter 2003):10-14.
- Nind, Melanie. "Stereotyped Behaviour. Resistance by People with Profound Learning Difficulties." In *Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance*, edited by Duncan Mitchell, Rannveig

- Traustadottir, Rohhss Chapman, Louise Townson, Nigel Ingham and Sue Ledger, 202-211. London: Jessica Kingsley Publishers, 2006.
- Noll, Steven, and James W. Trent Jr. *Mental Retardation in America: A Historical Reader*. New York: New York University Press, 2004.
- Ochs Elinor and Lisa Capps. "Narrating the self." *Annual Review of Anthropology* 25, no. 1 (1996): 19-43.
- Olkin, Rhoda. *What Psychotherapists Should Know About Disability*. New York: The Guilford Press, 1999.
- Park, Peter, Althea Monteiro and Bruce Kappel. "People First. The History and the Dream." In *Making equality: history of advocacy and persons with disabilities in Canada* (2003): edited by Deborah Stienstra and Aileen Wight-Felske; with Colleen Watters, 183-197. Concord: Captus Press, 2003.
- Pat Worth and the Name Change*, People First of Canada. Videocassette.
- People First of Canada, "About Us," <http://www.peoplefirstofcanada.ca>.
- People First of Canada. "Deinstitutionalization."
http://www.peoplefirstofcanada.ca/deinstitutionalization_en.php.
- Plummer, Ken. "The Call of Life Stories in Ethnographic Research" In *Handbook of Ethnography*, edited by Paul Atkinson, Sara Delamont, Amanda Coffey, John Lofland and Lyn Lofland, 395- 406. London: Sage Publications Ltd., 2001.
- Quinn Patton, Michael. *Qualitative Research & Evaluation Methods*. London: Sage Publications, Inc., 2002.
- Read Paul, Linda, RN, MN, CHPCN (C). "Relational Ethics: The Full Meaning of

Respect: A Book Review.”

http://www.phen.ab.ca/library_books/docs/Relational_Ethics.pdf.

Richardson, Laurel. “New writing practices in Qualitative Research.” *Sociology of Sport Journal* 17, no. 1 (2000): 5-20.

Schnarch, Brian. *Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities*. For the First Nations Centre and National Aboriginal Health Organization (2004).

Seale, Jane K. “The Same but Different: The Use of the Personal Home Page by Adults with Down’s Syndrome as a Tool for Self-Presentation.” *British Journal of Educational Technology* 32, no. 3, (2001): 343-352.

_____. “Researching home page authorship of adults with learning disabilities: Issues and dilemmas.” In Proceedings of International Education Research Conference AARE-NZARE, Auckland, New Zealand, November 30 - December 3, 2003.

Senehi, Jessica, Maureen Flaherty, Cyndi Sanjana Kirupakaran, Lloyd Kornelsen, Mavis Matenge and Olga Skarlato. “Dreams of Our Grandmothers: Discovering the Call for Social Justice Through Storytelling.” *Storytelling, Self, Society* 5, no. 2 (2009): 90-106.

Sikes, Pat and Gale, Ken. “Narrative approaches to Education Research.” *Research in Education (Resined)*, (2006).

<http://www.edu.plymouth.ac.uk/resined/narrative/narrativehome.htm>.

Smith, Brett and Andrew C. Sparkes. “Narrative and its potential contribution to

- disability studies.” *Disability & Society* 23, no. 1 (January 2008): 17–28.
- Statistics Canada. “Labour Force Participation and Unemployment rates by Disability Type, Canada, 2006.” *Participation and Activity Limitation Survey (PALS) 2006*.
<http://www.statcan.gc.ca/pub/89-628-x/2008007/t/5201154-eng.htm>.
- Stoneman, Zolinda. “Siblings of Children With Disabilities: Research Themes.” *Mental Retardation* 43, no. 5 (October 2005): 339–350.
- Stone-Mediatore, Shari. *Reading Across Borders: Storytelling and Knowledges of Resistance*. New York: Palgrave-MacMillan, 2003.
- The Freedom Tour*, People First of Canada, 2008, DVD.
- Valaskakis, Gail Guthrie. “Telling Our Own Stories: The Role, Development and Future of Aboriginal Communications.” Paper presented at the Colloquium for the Canadian Cultural Research Network/Réseau canadien de recherche culturelle, June 1998.
<http://www.arts.uwaterloo.ca/ccm/ccrn/documents/collg98valaskakis.htm>.
- Wall, Sarah. “An autoethnography on learning about autoethnography.” *International Journal of Qualitative Methods* 5, no. 2 (2006).
http://www.ualberta.ca/~iiqm/backissues/5_2/html/wall.htm
- _____. “Easier Said than Done: Writing an Autoethnography”, *International Journal of Qualitative Methods* 7, no. 1 (2008): 38-53.
- Walmsley, Jan. “Normalisation, Emancipatory Research and Inclusive Research in Learning Disability.” *Disability & Society* 16, no. 2 (2001):187–205.
- Walmsley, Jan and Kelley Johnson. *Inclusive Research Methods with People with*

- Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley Publishers, 2003.
- Wang, Caroline C., "Using Photovoice as a Participatory Assessment and Issue Selection Tool: A Case Study with the Homeless in Ann Arbor." In *Community-based Participatory Research for Health*, edited by M. Minkler and N. Wallerstein, 179-196. San Francisco: Jossey-Bass, 2003.
- Wiesner, Peter K. "Media for the People: The Canadian Experiments with Film and Video in Community Development (1992)," citing David Barker Jones, *The National Film Board of Canada; the development of its documentary achievement*, Stanford University Ph.D. Dissertation. Ann Arbor, Michigan: University Microfilms, 1977 in *Challenge for Change: Activist Documentary at the National Film Board of Canada*, edited by Thomas Waugh, Michael Brendan Baker and Ezra Winton, 73-102. Montreal & Kingston: McGill-Queen's University Press, 2010.
- Wolfensberger, Wolf. *A Balanced Multi-Component Advocacy/Protection Schema*. Toronto: Canadian Association for the Mentally Retarded, 1977.
- Willowbrook*, Directed by Ross Cohen, 2012, DVD.
- Worrell, Bill. *People First: Advice for Advisors*. Downsview: National People First Project, 1988.
- Worth, Pat. "Dare to Dream." Published on Inclusion Network.
<http://www.inclusion.com/respatworth.html>.
- Zingaro, Linde (2009): *Speaking Out: Storytelling for Social Change*. Walnut Creek, CA: Left Coast Press, INC.

Zizek, Slavoj. *Violence: Six Sideways Reflections*. New York: Picador, 2008.

Annexe 1: Part I: Consent to Participate



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Research Project Title:

Look, Listen and Learn: Collaborative video storytelling by/with people who have been labelled with an intellectual disability.

Researcher: Josée Boulanger, Master's student in the Interdisciplinary Disability Studies Program at the University of Manitoba.

PART I: Consent to participate

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your role will be. Please take the time to read this carefully and to make sure you understand what it all means. If you would like more information, feel free to ask. You will have your own copy of this consent form to keep with you for your own records.

What is the goal of Josée's research project?

The goal of her research project is let people know how *The Freedom Tour* documentary film and the *Label Free Zone* web project were created. Josée was the filmmaker and facilitator

involved in these two projects. She will write a story from her own perspective so that others can learn from her experience of making video stories in collaboration with People First self-advocacy movement members.

In this story, Josée Boulanger will talk about *how* she collaborated with People First members to create these two projects. She will reflect on her role, her work as a filmmaker and project director and how these two experiences have changed her personally and professionally. She will share, for example, stories about the scriptwriting process, research process, search for funding, development of collaborative methods, video editing, camera work and interviewing and public screenings.

Josée's story will be written in plain language to make it accessible to as many people as possible. She hopes that her first-hand story about collaborative video storytelling will be useful to other researchers, artists, filmmakers and advocates interested in using video storytelling for advocacy purposes. She also hopes this will be an opportunity for her to grow as a community filmmaker working with people who have been labelled with an intellectual disability.

What information does Josée need from *you*? Josée Boulanger needs to know if it's ok to name you in her story about *The Freedom Tour* and the *Label Free Zone*.

Why does she need your consent?

Josée's story about her experiences of working on *The Freedom Tour* and the *Label Free Zone* will be made public just like the documentary and the website are public. Anyone will be able to read it.

How can you make your decision?

You will get the story on paper and in large print. You can read it on your own before you meet with Josée or you can ask someone you trust to help you read through it.

Once you have read the story, you must decide if:

You want to remove your name from Josée's story.

You want to make changes to the story and keep your name in it.

You want to leave the story the way it is.

If you decide to remove your name from Josée's story, it will be removed. If you decide to keep your name in the story, it means your name will appear in Josée's final story about her experience as filmmaker/facilitator for *The Freedom Tour* and *Label Free Zone* projects. You can ask Josée to make changes to the story if you don't agree or you don't like the way she tells the part that talks about you.

How will your feedback be recorded?

Your feedback will be recorded in person with Josée on audio-tape. The audio-tapes will be kept in a filing cabinet in Josée's home office. Your feedback about the story will not be available to the public. Only Josée and her thesis supervisor can listen to the audio tapes containing your feedback. Josée will listen to your feedback to know if your name must be removed, if a part of the story must be changed or if you wish to leave the story the way it is. She will be the person typing your comments into a computer.

Josée can meet you at home to record your feedback or any other quiet place you choose. This meeting will take about 2 hours of your time. If a face-to-face meeting is not possible, Josée will contact you over the telephone.

Where will this story about Josée's experiences go?

Josée's story about her experience as filmmaker/facilitator for *The Freedom Tour* and *Label Free Zone* projects will be published as part of her Master's thesis and will be available to the public on the Internet as a word document supported by drawings and pictures.

Will you receive compensation for reviewing Josée's story?

To recognize your contribution to Josée Boulanger's research study, your name will be mentioned in the credits as a story consultant. You will also receive a paper copy of the final study.

Your signature means that you understand what you have just

The audio tapes will be destroyed once the research has been completed, in other words before July 2013.

read and that you want to participate in Josée's research project by reviewing her story.

You can decide at any time to stop participating in this research project. Feel free to ask questions about the research project and about your role at any time during your participation.

Principal Researcher: Josée Boulanger
Researcher's supervisor: Nancy Hansen

This research has been approved by the Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Your name in print: _____ Date _____

Your Signature _____ Date _____

Researcher's Signature _____ Date _____

(Josée Boulanger)

Annexe 2: Part II: Consent to Publish



UNIVERSITY Disability Studies
OF MANITOBA An Interdisciplinary Program

Room 128 Education Building
University of Manitoba
Winnipeg, Manitoba
Canada, R3T 2N2
Telephone (204) 474-7017
Fax (204) 474-6676
disability_studies@umanitoba.ca

Research Project Title:

Look, Listen, Learn: Collaborative video storytelling by/with people who have been labelled with an intellectual disability.

Researcher: Josée Boulanger, Master's student in the Interdisciplinary Disability Studies Program at the University of Manitoba.

PART II: Consent to publish

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your role will be. Please take the time to read this carefully and to make sure you understand what it all means. If you would like more information, feel free to ask.

You will have your own copy of this consent form to keep with you.

What is the goal of Josée's research project?

The goal of her research project is let people know how *The Freedom Tour* documentary film and the *Label Free Zone* web

project were created. Josée was the filmmaker and facilitator involved in these two projects. She will write a story from her own perspective so that others can learn from her experience of making video stories in collaboration with People First self-advocacy movement members.

In this story, Josée Boulanger will talk about *how* she collaborated with People First members to create these two projects. She will reflect on her role, her work as a filmmaker and project director and how these two experiences have changed her personally and professionally. She will share, for example, stories about the scriptwriting process, research process, search for funding, development of collaborative methods, video editing, camera work and interviewing and public screenings. Josée's story will be written in plain language to make it accessible to as many people as possible. She hopes that her first-hand story about collaborative video storytelling will be useful to other researchers, artists, filmmakers and advocates interested in using video storytelling for advocacy purposes. She also hopes this will be an opportunity for her to grow as a community filmmaker working with people who have been labelled with an intellectual disability.

Do you want to be named in Josée's story?

I do NOT WANT to be named in Josée's story about her experiences as filmmaker/facilitator of *The Freedom Tour* and *Label Free Zone* websites.

I WANT to be named in Josée's story about her experiences as filmmaker/facilitator of *The Freedom Tour* and *Label Free Zone* websites. I agree with the story. No changes are needed.

Where will this story about Josée's experiences go?

Josée's story about her experience as filmmaker/facilitator for *The Freedom Tour* and *Label Free Zone* projects will be published as part of her Master's thesis and will be available to the public on the Internet as a word document supported by drawings and pictures.

Will you receive compensation for reviewing Josée's story?

To recognize your contribution to Josée Boulanger's research study, your name will be mentioned in the credits as a story consultant. You will also receive a paper copy of the final study.

Your signature means that you understand what you have just read and that you want to participate in Josée's research project by reviewing her story.

You can decide at any time to stop participating in this research project. Feel free to ask questions about the research project and about your role at any time during your participation.

Principal researcher: Josée Boulanger
Researcher's supervisor: Nancy Hansen

This research has been approved by the Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Your name in print: _____ Date _____

Your Signature _____ Date _____

Researcher's Signature _____ Date _____
(Josée Boulanger)

Annexe 3: Letter of Agreement



UNIVERSITY OF MANITOBA Disability Studies
An Interdisciplinary Program

Room 128 Education Building
University of Manitoba
Winnipeg, Manitoba
Canada, R3T 2N2
Telephone (204) 474-7017
Fax (204) 474-6676
disability_studies@umanitoba.ca

Research Project Title: Look, Listen, Learn: Collaborative video storytelling by/with people who have been labelled with an intellectual disability.

Researcher: Josée Boulanger, Master's student in the Interdisciplinary Disability Studies Program at the University of Manitoba.

Letter of agreement
between
People First of Canada
and
Josée Boulanger

This letter of agreement should give you the basic idea of what this research project is about and what is being asked of you as an organization. If you would like more information, feel free to ask the main researcher Josée Boulanger or her thesis supervisor Nancy Hansen.

You will have your own copy of this letter of agreement to keep

with you for your own records.

What is the goal of Josée's research project?

The goal of her research project is to learn from her experiences as filmmaker/facilitator of two collaborative media projects involving people who have been labelled with an intellectual disability. These two media projects were *The Freedom Tour* documentary film and the *Label Free Zone* website. Between 2006 and 2009, Josée worked with members of People First of Canada to create these two projects.

For her master's thesis, Josée will research her own experience and write a story from her own perspective about this. This is also called writing an auto-ethnography. In this auto-ethnographic story, Josée will mix theory or ideas with research and information about other collaborative media projects with people who have been labelled and with people without disabilities.

Josée will not be speaking for or on behalf of People First of Canada. She will be speaking for herself using the pronoun “I” and “my experience as a...”.

Why is Josée doing this research?

She hopes that her story about collaborative video storytelling will be useful to other researchers, artists, filmmakers and self-advocates interested in video storytelling for advocacy purposes. She also hopes this will be a chance for her to learn from her experiences and to grow as a community filmmaker working with people who have been labelled with an intellectual disability.

Your signature means that you understand that Josée Boulanger is doing self-study (auto-ethnographic) research about her experience as filmmaker/facilitator involved in an

activity led by People First of Canada.

Principal Researcher: Josée Boulanger
Researcher's supervisor: Nancy Hansen

This research has been approved by the Joint Faculty Research Ethics Board.

If you have any concerns or complaints about this research project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this letter of agreement has been given to you to keep for your records and reference.

By signing this letter of agreement, People First of Canada understands that Josée Boulanger is in not representing the view or opinions of People First of Canada as an organization. She is writing from her own perspective and about her own experiences as filmmaker/facilitator for *The Freedom Tour* documentary and the *Label Free Zone* website. The focus of her research is her own experience in the role of filmmaker and facilitator.

Your name: _____ Date _____
(PFC Representative)

Your Signature _____ Date _____
(PFC Representative)

Researcher's Signature _____ Date _____
(Josée Boulanger)