Mobilizing New Meanings of Disability and Difference

Includes:
Final Report

By Amber Flynn

Completed for: YWCA Peterborough Victoria and Haliburton
Supervising Professor: Dr. Nadine Changfoot
Trent Centre for Community-Based Education

Department: Political Studies
Course Code: POST 4070Y
Course Name: Community engagement and leadership internship in the era of globalization
Term: Fall/Winter
Date of Project Submission: April 2013

Project ID: 4373

“Mobilizing New Meanings of Disability and Difference”

April 22nd 2013
POST 4070Y Community Engagement Internship
Host Facilitator : Nadine Changfoot, POST Trent University
Host Organisation: Joëlle Favreau, YWCA Peterborough, Victoria, and Haliburton
Student Researcher: Amber Flynn
Project Re*Vision

Abstract:

The literature review discussed how common stereotypes, stigmas and misconceptions that form around disability often create the negative discourses which circulate within society. These discourses construct false labels and categories which negatively construct an individual's potential success, acceptance within society, personality and identity in a derogatory manner. These stereotypes can increase vulnerability for individuals with a disability and difference within the healthcare setting and in educational institutions. Structural, financial, cultural and professional barriers exist and hinder one's ability to receive inclusive and humane levels of care within the medical field and society. Arts bases research and expression provide alternative ways to create societal change and understanding within one's self and within society to create inclusion for all. Art bases expression can assist in educating the public and creating a broader understanding, compassion and inclusion for disabled persons. Equal treatment and acceptance within society is desires; art based expression and adequate education to the public will allow equality and fairness within all aspects of society for disabled persons to occur.

Keywords: Inclusion, art bases expression, disabled, able-bodies, barriers, care, and acceptance.

Acknowledgements

I would like to thank my host facilitator Nadine Changfoot, her hard work, dedication and superior knowledge in this area of study and within community based education has truly helped to guide the process every step of the way. Her dedication to her student's success surpasses all others. Without her help the overall experience and final product would not have been so rewarding and enriching.

The Trent Center for Community Based Education preformed all of the preliminary work necessary in order to make my project along with many others possible. Without the help of Andy Cragg and Todd Barr encouraging all students, providing feedback, constructive tips and informative workshops the project would not have went so smoothly.

Joëlle Favreau has made many efforts to provide a space for the digital story workshops to occur. She has dedicated herself to create a safe forum for all participants in the workshops, and the emerging women's group, Women Building Inclusion. She has been available for clarification and support throughout the process.

Project Re*vision has provided all of the necessary tools and equipment in order for the digital story workshops and process to occur. Without Project Re*visions drive to create inclusion for women with a disability and difference I would have never been fortunate enough to participate on this project.

Table of Contents

Introduction

The community based education project, “Mobilizing New Meanings of Disability and Difference” was created to assess the barriers that face many women with a visible and invisible disability and difference in Canadian society; the project had a primary focus on the realm of healthcare and institutional structures. The project has been shaped by many contributing elements. The digital story making process allows for women to make a short two-three minute film that uses images, music, narrative and one’s own voice to express a person’s individual story, knowledge and understandings of disability and difference. The process of art based expression can emotionally empower the story teller. Art allows for the audience to have a deepened understanding of the hardships that face many persons with disabilities in a way other mediums cannot. This communal understanding by all community members will help to shift the common misconceptions of disability and difference in order to advance health care, educational and community inclusion for women with disabilities.

The literature review was another critical element to the project as described above; it helped to identify the stereotypes that arise in modern society that are commonly accepted as facts and ‘truths’. After identifying the social dilemmas that resonate within society, one can see how these negative discourses must be reshaped in order to create total inclusions for women with disability and difference. If the barriers in receiving adequate and humane healthcare and the negative perceptions within society are broken down, acceptance is possible. If art based expression and a wider truthful knowledge are accessible on disability and difference to the public, total inclusion and recognition within Canadian society is possible. With the coordinated efforts of both disabled and able-bodies allies, positive and permanent social change can occur.

Video project: Digital Stories

Earlier digital stories made prior to Project Re*Vision and informed Project Re*Vision can be found at the "Envisioning New Meanings of Disability and Difference" website. Project Re*vision is currently in the process of making a website to access their digital stories.

http://www.envisioningnewmeanings.ca/

Literature Review:

Introduction

The liberation of disabled persons is a rather recent phenomenon; prior to the 1970's and throughout numerous centuries, disabled persons were depicted in a derogatory fashion by all levels of society. Disabled persons were seen as defective, weak and incapable beings who were unworthy of equal treatment and status in comparison to able-bodied men and women within Western and global societies. Despite common perceptions, many of the demeaning and negative stereotypes that surround disabled persons were not created from naive uneducated individuals; on the contrary, this restricting rhetoric was embedded within the institutional, medical and scholarly language and created from educated and knowledgeable minds from the past. These dark depictions of persons with disability have been perpetuated into modern society and are commonly used within everyday conversations and interactions. Disabled persons rarely have an outlet to counter the dehumanizing language and images used against them until the slow emergence of the disability sub-culture. Within institutional settings such as the medical field or educational system, often professional persons do not acknowledge that their descriptive terminology can be crippling and dehumanizing which often create barriers for disabled persons to access care. For a person to be described as a "case" or "study patient", is demoralizing; people do not always acknowledge the power language can hold. When negative labelling and categorization of disabled persons occurs; fundamental elements of one's personality and identity can be construed and negatively reshaped, which creates a form of otherness (Wendell 1996, 58). This "case study" is no longer a unique individual with talents, self worth and optimism; they are a label: illness, disease and treatment options.

When dehumanizing terminology and language is used within institutional settings it further amplifies its use within society and causes a hyper-visibility and disempowerment of disabled persons. Many obstacles must be overcome in order to alter the medical and institutional perceptions of disability. These perceptions often create structural, financial, societal and professional barriers; as well as barriers to one's personal independence and barriers in receiving preventative care measures. Many persons with disability face an identity crisis when attempting to combat these inaccurate stereotypes and barriers in life and create their own niche within society. One way to fight back against the derogatory gazes of the able-bodied world is to stare back into the face of the oppressors through art-based expression, theater, poetry, literature and various forms of artistic agency. Art forms are able to reach a person or an audience in ways, unlike facts and statistics. Persons with disabilities are able to collectively unite and fight oppression by generating awareness about the economic, societal and personal levels of inequality, vulnerability and violence many disabled persons encounter daily. This literature review will demonstrate how art-based expression can be used to decrease levels of vulnerability and violence by creating new forms of collective consciousness through the reconstruction of mainstream negative stereotypes, also by decreasing identity conflicts, which are often, created by the use of restricting, false and categorizing rhetoric within society and institutional structures.

Learning Styles

Manuela Ferrari in her paper titled "My Journey Through my Qualifying Exam using Reflexivity and Resonant text: 'what I know'; 'how I know it'; and 'how I experience it'", depicts a fascinating understanding of the mainstream medical and scientific discourses which circulate within society, such as the preferred institutional methods of learning which are verbal/linguistic and logical/mathematical styles (Ferrari 219).Ferrari equally embraces a humanistic element which explains that although society prefers only two of the eight possible learning styles and evidently ignores visual/spatial, musical/rhythmic, bodily/kinesthetic, interpersonal, intrapersonal, and naturalistic ways of learning; individuals who construct their knowledge based on these alternative methods should neither feel inadequate nor need to develop low self-esteem from their perceived intellectual 'failures' (Ferrari 219). She discussed along with many other scholars involved within Disability Studies that identity issues and crisis are heavily prevalent among men and women of the disabled community. The constant feelings of failure and intellectual inadequacy in comparison to their able-bodied and able-minded, friend, family and community members can take a devastating toll when developing one's own self image, worth and character.

Society's Perceptions of Disability: In the past

It is not a secret that disabled people throughout history have not been treated as equals in comparison to their able-bodied peers. Barbara Arneil[1] in her book Recognizing Difference/Achieving Equality: Multiculturalism and Gender Justice presents historical evidence that all persons including 'enlightened' intellectuals and liberal thinkers were also guilty of publicly excluding and stereotyping persons with disabilities throughout the centuries and into the modern era. Some of these revered theorists she refers to are Immanuel Kant, David Hume, John Rawls, John Locke and Charles Taylor who often "exclude 'disabled persons' from the

---

[1] Arneil is a noteworthy academic; she has made numerous advancements within the scholarship of Feminist and Disability studies. Her specializations are often within the areas of Identity Politics; as well as the History of Gender, Political Thought and Theory. Her dedication to identity and disability issues has created a strong basis for her predecessors to grow upon. She is a scholar who is often cited for being a pioneer for her contributions to these disciplines.

principles of justice, personhood and citizenship on the basis that their physical and mental limitations make them something less than free and equal beings"(Arneil, *Recognizing Difference* 4). These centuries old exclusionary practices place disabled persons on the peripheries of society and drastically increase their levels of vulnerability and victimhood to crime and violence. These common crimes result in verbal, emotional, physical and sexually abusive acts against the disabled body (Arneil, *Self Image* 221). Also, disabled persons were barred from formal participation in public settings; many disabled people were unable to make a distinctive mark on their cultural demographics and were excluded from any form of public expression (Arneil, *Self Image* 222). Within the modern era, many disabled persons have become politicized and activists in creating social inclusion. They hope to create their own distinguishing mark and niche within local and global communities. By doing so, they are also attempting to combat the injustices that have faced disabled individuals in the past. Modern technological advancements have furthered disabled persons capacity to articulate themselves through a multitude of different media such as the written word, public speeches, protest, theatrical expression, artistic demonstrations, digital storytelling and self advocacy.

Emergence of Disability Sub-Culture:

Through these acts of self expression, a disability sub-culture is slowly emerging within the twenty-first century; however until recently there was no formal public space for disabled persons to congregate. Arneil and Susan Wendell author of the The Rejected Body: Feminist Philosophical Reflections on Disability, agree that disabled people are one of the most vulnerable minority groups within modern society (Wendell 1996, 59-60). As Roger Nash Baldwin has stated "silence never won rights. They are not handed down from above; they are forced by pressures from below" (Clifford 1). Disabled persons had to actively campaign for numerous years to achieve awareness of their existence and needs within society. Official equality and inclusion for disabled individuals was not recognized until December 9th 1975 (Department of Economic and Social Affairs). Equality was granted under the formation of the United Nations Declaration on the Rights of Disabled Persons1975. This was the first form of universally recognized legislation that officially acknowledged the rights and liberties of disabled persons. (Department of Economic and Social Affairs).

Barriers in the Disabled World:

Although official universal and domestic legislations have been formed within Canada and the United States, societal stereotypes and barriers which restrict disabled persons still commonly exist. These barriers are present within daily life and frequently appear within formal institutions such as transportation, media depictions, educational environments and medical facilities. Self advocacy and creating awareness has only recently been starting to shake the binaries that constrict societal perceptions of disability and difference. Small social stigmas associated with disability can have long term ramifications and negative effects on many persons. It cannot be simply coincidental that disabled people often have the lowest socio-economic status compared so all other minority groups. People with disabilities are presently the largest minority group within the United States (Fox, Lipkin 83). Mari-Lynn Drainoni, one of the collaborating authors of <u>Cross-Disability Experiences of Barriers to Health-Care Access Consumer Perspectives</u> explains that disabled Americans “are less likely to be able to work, more likely to have low household incomes, and are more likely to be dependent on federal and state-funded health insurance programs such as Medicare and Medicaid than those without disabilities” (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 102). Statistics like this do not stand alone. Arneil, Lipkin, Brueggemann, Fiorilla and their affiliates would agree that the socio-economic state of disabled persons is lower compared to able-bodied persons. Brenda Brueggemann who will be discussed in detail later on, states, “there are, according to one recent estimate, fifty-six million Americans with a disability, a stunning one-half who are underemployed or unemployed” (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 371). Within Canada similar statistics exist. Statistics Canada expressed that according to the 2006 Participation and Activity Limitation Survey, approximately forty-two percent of persons between the ages of fifteen and sixty-four who reported having a disability were unable to work (Galarneau 1). Also, Statistics Canada suggested that approximately fifty-five percent of men and thirty-nine percent of women without a permanent disability were physically able to work a full-time schedule each year (Galarneau 1). This is compared to, twenty-one percent of disabled men and fourteen percent of disabled women who possess the ability to work full time (Galarneau 1). Men with a permanent disability are eight times more likely to reside in the lowest income bracket. Permanently disabled women are four times more likely to live within the lowest socio-economic class compared to able-bodied Canadians. Later within the 2013 calendar year, the Canadian government plans on updating this information.

Ann Fox and Joan Lipkin who are authors of a compelling article which discusses the practice of reclaiming the female disabled body through theater called, Res(Crip)ting Feminist Theater Through Disability Theater: Selections from The DisAbility Project also agree when stating “people with disabilities are the most under-employed population in the country. This is mostly because of our [Americas] public transportation systems which make it difficult for them to obtain jobs. Or, employers simply will not hire them. Disabled persons have the highest unemployment rate of any group, it is somewhere between seventy-two and ninety percent" (Fox, Lipkin 83). It seems perplexing that all scholars can agree that the framework of society places disabled people and primarily women with disabilities in extremely vulnerable positions and forces them to become dependent on others and the state. One begins to question why these figures are true; and which underlining social problems exist within the twenty-first century to allow disabled persons to remain on the margins of Western society. Why is it so difficult for disabled persons to obtain the “normal” life which they long for? It could be argued that these levels of exclusion, vulnerability and hardship can be attributed to the societal stereotypes that are knowingly and unknowingly perpetuated within society.

Identity: The Power of Language

These stereotypes commonly reflect the outer appearance of many disabled individuals who are unable to hide from the piercing gaze of naive Western onlookers. Many individuals are unaware that an arguably ‘uncomfortable’ stare by an individual upon a disabled person can create an atmosphere of being unwelcomed and undesired. Another of Barbara Arneil texts titled, Disability, Self Image, and Modern Political Theory points to many of the common vernacular terms and shortcomings within society that are damaging, yet, often overlooked. Arneil first illustrates the oppressive terminology used by most individuals throughout the decades to describe persons with disabilities, such as “infirm, feeble-minded, invalid, cripple, incapable, abnormal, and deviant and handicap” (Arneil, *Self Image* 219). She argues that many people do not recognize the dangerous power which negative language holds over an individual (Arneil, *Self Image* 219). For a person with a visible or invisible difference, this type of derogatory language, imagery and inaccurate stereotypes can cripple one’s confidence and attitudes toward their self image and personal identity.

Categorization and Labelling:

The categorization of one’s identity by societal members, rather than oneself can be devastating for any person, able-bodied or not. Anyone who is mistakenly labelled and confined into a stigmatised and marginalized group by society against their will is bound to form inter-personality conflicts (Wendell 1996, 66). From within my own personal experience, being a woman with a disability and difference, I rebelled in my youth against being stigmatised and isolated as the “special child” within the educational institution. I was attempting to find myself; and my place among my community, family and peers. When wrongfully categorised and secluded within a ‘resource room’, I felt ostracised and excluded from my classmates. My gender, ethnicity, sexual orientation, religious affiliation and cultural distinctions were overshadowed by my disability. I did not feel like I was provided the equal opportunity to develop and understand myself, as my disability eclipses my potential to be seen as intelligent, vibrant, accepted and equal.

For physically disabled women, societal first impressions are not formed through important labels and characterises such as wife, mother, daughter, friend, community member, employee and student (Wendell 1996, 71). When society forgets the `subtext` of a person’s character, which is a person’s, age, sexuality, gender, class, race and ethnicity and attempts to solely categorise an individual as disabled, a multitude of important personal attributes can be overlooked and undermined as I have personally experienced(Wendell 1996, 71). Simi Linton is a scholar and woman with a physical disability. Her disability is a result of a fatal car accident which devastatingly killed her husband and confined her to a wheelchair. She has found strength within her disability and discusses her experiences of rehabilitation and coping with a disability within her text Claiming Disability Knowledge and Identity. She combats many identity issues which face numerous disabled persons. Linton explains that one's disability should be seen as a secondary characteristic, and not a defining "marker of their identity"(Linton13). As a result of the fact that she is a women living with a disability her insight and personal experience add a crucial element to the scholarship as her personal story is able to reach a broader audience. Her educational background is in psychology; however after the accident she decided to focus her efforts on creating inclusion for disabled persons, increasing community awareness and has attempted to disrupt mainstream stereotypes within the scholarship of Disability Studies[2].

Otherness:

Disability is a double edged sword; as Wendell suggests, this is a result of the fact that one's disability may make an individual appear inherently unique and interesting, however, their disability disguises their other rewarding and valuable personality characteristics; and furthers the process of marginalization (Wendell 1996, 66). Nira Yuval-Davis author of "Belonging and the Politics of Belonging" agrees with Arneil, Wendell and Linton when discussing that the concept and boundaries associated with the "us and them" mindset of society must end in order to obtain full inclusion and acceptance of disabled persons (Yuval-Davis 199).The disabled body is often viewed in two forms. The first is the disabled hero, which demonstrates a "heroic feat of control against the odds" (Wendell 1996, 64). These persons are publically rewarded and recognized for their accomplishments and triumphs for defying the limitations of their body and

---

[2] Her depictions of her personal experiences are intertwined within the experiences of others with disabilities, and at times it is difficult to distinguish as to whose experience she is referring. To her credit, although her explanations are foggy at times they are fundamentally critical in understanding the interworking of the physical and psychological state of a woman with disabilities which is not represented within comparable texts.

disability. Although recognitions for one's abilities are always essential, she states that the vicious cycle of the "otherness" is also furthered through the creation of the disabled hero. Often, a person who is able to overcome their disability and prevail physically, economically or intellectually, frequently have a large abundance of resources at their disposal; this is in contrast to the many marginalized disabled persons who reside in the lowest socio-economic classes (Wendell 1996, 64). Disabled heroes like Steven Hawking although wonderful individuals, as Wendell describes, can create a "false impression that anyone is able to overcome their disability" (Wendell 1996, 64). Disabled persons are constantly compared to their able-bodied counterparts and the societal stereotype such as the disabled heroes may only increase feelings of inadequacy and a sense of personal failure, thus furthering levels of depression, despair, vulnerability and identity crisis among disabled women and men. For the reasons that disability subculture has not become mainstreamed and widespread within Canadian and global society, many of the same desires, goals and ambitions of able-bodied persons are often yearned for by disabled persons (Wendell 1996, 59-60)[3]

Art-Based Expression: Creating a Disability Sub-culture:

If disability sub-culture became recognized and accepted within society, disabled youth would no longer only look to able-bodied role models for setting personal goals and ambitions. Feelings of anxiety, inadequacy and shame associated with their disability and difference would

---

[3] Wendell did not explore the counter argument to the disabled hero which conveys that her argument may be too heavily one sided. Although she did a fantastic job describing the hardships associated with adhering to media depictions of the disabled hero and societal expectations, she did not discuss how perhaps younger generations of disabled persons could gain a positive role model from a relatable figure. Her argument of expendable resources does hold merit, however, the power of personal agency and belief can be stronger than financial resources for some strong-willed individuals. To Wendell's credit, her attention to detail and dedication to creating equality has provided the review with many contrasting and concrete concepts and was fundamental to the review of literature within the scholarship of disability.

be transformed into a positive understanding of self. Politicization and self-advocacy help in bridging the gap between able-bodied and disabled persons; however, arguably art-based expression may become the next ‘wave’ in creating inclusions and acceptance of disabled persons. The DisAbility Project, based out of Saint Louis Missouri, discussed by Ann Fox and Joan Lipkin, is an excellent example of how disabled persons can be provided a space to articulate themselves through theoretical expression, in order convey their own personal experiences and understanding of disability. Lipkin when describing the purpose of the DisAbility Theater stated, “we are equal parts art and advocacy. And the minute we fail to delight, surprise, move or mystify in how we say things as well as what we say, we've lost our focus” (Fox, Lipkin 82). The DisAbility Project encompasses many disabled persons within its mandate of acceptance, which includes, “paraplegia, quadriplegia, AIDS, multiple sclerosis, cerebral palsy, stroke, blindness, bipolar disorder, cancer, spina bifida, muscular dystrophy, spinal cord injury, asthma, polio, epilepsy, amputation, depression, cognitive disability, and alcoholism”(Fox, Lipkin 82). Disabled youth may be able to personally relate to the cast, because they are ordinary people from similar economic backgrounds and life experiences. Disabled youth can reflect inwards and understand that they are not barred from equal participation within society for their difference, and that a multitude of possibilities exist. Katherine Sherwood, author of Art, Medicine, and Disability has confirmed that positive role models can be created from expanding disability culture. She states, “by working with disabled artists, students shift their perspective on disability in a profound manner. Often, they find themselves in situations that push their personal boundaries and blur the distinction between able-bodied and disabled. Inevitably, this causes them to re-evaluate their conception of the normative” (Sherwood 193).

Similar Canadian groups exist such as RARE Theater based in Toronto and Project Re-vision based within numerous Ontario communities such as Guelph, Peterborough, Barrie and Toronto. RARE, is a unique theatrical display currently showcasing a cast consisting of nine individuals with Down syndrome who express their experiences living with their disability and their hopes and desires for their future selves (Crew). Project Re-vision focuses working with women with disabilities as well as healthcare providers to shift the common misconceptions of disability and difference in order to advance health care, educational and community inclusion for women with disabilities. Digital stories are short self reflexive films which uses images, music, narratives and one’s own voice to reach a broader audience and create deeper and personal connection with the listeners. Artistic expression is a forum which constructs avenues into the public sphere which many disabled women and persons may not have access to within their daily lives. If disabled culture was mainstreamed within dominate society, many persons would recognize that although there are significant differences in the lived identities and experiences of nondisabled and disabled persons; actively integrating disabled sub-culture into mainstream society “underscores that there are concerns relevant to the disabled community that have real implications for nondisabled individuals as well”(Fox, Lipkin 82). Art-based expression encourages youth and adults to explore their creativity and develop themselves into the “proud, angry and strong” persons they are; however, the looming notion of tragedy surrounding disability exists despite activists’ and artists’ desires to combat it on stage (Eisenhauer 9).

Rare Performers of 2012-2013 showcase Toronto Ontario.

Nestruck, J. Kelly. *Members of the cast of Rare*. 2013. Members of the cast of Rare, Toronto. *The Globe and Mail*. Web. 2 Feb. 2013.

Victimhood of Disability:

The second powerful stereotype which faces disabled persons is the idea of the disabled victim which Linton attempted to combat within her own personal memoir. Wendell explains that disabled persons are frequently associated with “tragic loss, weakness, passivity, dependency, helplessness and incompetence”.(Wendell 1996, 63). A quote from Wendell describes the negative connotation associated with the weak and fragile disabled persons and their perceived place within Western medical knowledge:

> “In the societies where Western science and medicine are powerful culturally, and where their promise to control nature is still widely believed, people with

> disabilities are constant reminders of the failures of that promise, and of the inabilities of science and medicine to protect everyone from illness, disability and death. They are 'the Others' that science would like to forget. In a society where there are strong ideals of bodily perfection to which everyone is supposed to aspire, people with disabilities are the imperfect 'Others' who can never come close enough to these ideals.(Wendell 1996, 63).

Hyper-Visibility and Disempowerment:

This depiction of the disabled victim makes difference hyper-visible and unnerving.(Wendell 1996, 65).The instruments created to aid disabled persons help in furthering hyper-visualization and societal pity upon disabled persons. A wheelchair, canes, walkers, communication device and other instruments, construct the capabilities of the disabled body as lesser than an able-bodied person; this is due to its reliance on technological aids. Medical personnel such as doctors, nurses, psychologists, therapists and physiotherapists may "tend to universalize" disability (Wendell 1996, 71). This occurs when a scientifically recognized description of a disability or diagnosis is used to generalize the experiences of all persons who have such ailment. This universalized knowledge that is created about one's difference only allows the physical imperfections to be acknowledged and again the personal experiences, "social interactions, opportunities, economic welfare, and community status is overlooked" (Wendell 1996, 71). As a result of this personal disconnection between healthcare providers and patients, many persons with disabilities and non-disabled persons associate hospitalization or medical treatments as inherently negative experiences. As Brueggeman states, when a disabled person is viewed simply as an "object of study…they have become disempowered"(Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 372). Many persons feel objectified, misunderstood and often overlooked by healthcare providers when entering busy medical facilities. For example, many adults with spina bifida can recall instances where they were "paraded naked in front of medical professionals in auditorium-type settings," and experienced "painful medical procedures being done without explanation, compassion, support systems present or informed consent"(Van Daalen-Smith 266). Disempowerment can lead to distrust, insensitivity, disrespect, shame and reluctance to return and receive future treatments (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 103).

Medical Perspectives:

According to Mari-Lynn Drainoni, Elizabeth Lee-Hood, Carol Tobias, and Sara S. Bachman authors of "Cross-Disability Experiences of Barriers to Health-Care Access Consumer Perspectives", roughly twenty percent of Americans have medically recognized disabilities. (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 101). This medical research has stood alone within the evidence and knowledge it has articulated to a multitude of audiences within difference disciplines of the medical knowledge, institutional policy, disability studies and greater American public. Similar statistics exist for the Canadian population. It is estimated that approximately "4.4 million Canadians living in households reported having an activity limitation yielding a disability rate of 14.3%" in 2006 (Galarneau). Hundreds of personal accounts of persons with disabilities who have vocalised their personal insights into the positives and negatives associated with the institution of healthcare have surfaced within recent years. Disabled persons have expressed their discontentment with medical institutions and common barriers in receiving care such as accessibility, financial issues, communication hurdles, personal and cultural barriers, as well as a lack of personal connection and humane treatment (Roscigno

21). These obstacles in receiving care exist within Canada and the United states. With approximately twenty percent of the American population amounting to roughly fifty-six million people being disabled; it was interesting to find that this group had the largest dissatisfaction rate when ranking their interactions with the healthcare system (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 101). Many disabled persons do not feel like their opinions and desires are accounted for within the medical field. These discursive interpretations for regarding care by health care providers often further personal and cultural barriers to care. Medical knowledge is perceived as superior to personal requests and understanding of the body; due to this perception, disabled persons can often feel neglected and forgotten within the field of care. A personal experience by a woman with severe mobility issues, explains her negative encounters with medical personnel, she states:

> I explain coolly that I can get hurt if handled the wrong way.... I want one of my people to do it.... The next thing I know, I'm being grabbed by two women in shower caps. One has my knees and the other is scooping up my shoulders. It's the wrong lift. All my weight will hang from two sets of fragile joints. My curvy spine will dangle unsupported, putting the spinal cord and that bundle of nerves at risk. In a microsecond of terror I see the whole calamity. I mouth the word "Stop!" I'm despairing. They won't even notice. They won't understand. But one of them notices. Stops. Looks. ‘Are you saying 'Stop'?’ I nod my head. ‘We're just going to put you in this bed and then we'll be done.’ ‘No,’ I mouth. ‘No.’ ‘You don't want us to move you? We'll be careful. It'll just take a second....And a second is all it takes. A second in which panic sends my mind out of my body, as abused minds are said to flee when denied control over abused bodies, to look down at what seems like a pale shriveled corpse being tossed like trash from one place to another.... What silenced me was not voice-lessness, but being in a place where what I said and what I wanted didn't matter.(Roscigno24).

Episodes of persons’ feeling ignored and disregarded within the medical field are prominent within a North American setting and globally. Western perceptions of medicine can cloud personal understandings of self and dismiss them as obsolete.

Barriers to Accessing Care:

Although disabled persons make up more than "one third of all physician visits; over sixty percent of all overnight hospital stays, and over forty percent of all prescriptions and refills" in the United States, with similar percentages within Canada (with disability effecting one in seven Canadian citizens), many have difficultly accessing healthcare (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels102). One might question why this group who commonly requires medical attention has high levels of dissatisfaction and delayed access to care. A reported thirty to fifty percent of disabled adults express dissatisfaction towards medical care within the United States (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 103). Instances of frustration often occur due to structural barriers. Structural barriers often include one's lack of financial eligibility due to low income issues. Financial barriers affect a person's accessibility in receiving expensive treatments, prescription drugs, prosthetic limbs or obtaining necessary equipment and tools such as wheelchairs, communication devices or personal care providers. Financial barrier restrictions also exist if required medications and procedures were not deemed "medically necessary or rehabilitative" by one's insurance providers (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 106). This is common with physiotherapy or chiropractic work as it is not always covered by the Canadian Federal Health Insurance Plan or the Ontario Health Insurance Plan. Lacking prescription coverage, limited equipment repairs to damages wheelchairs and essential medical supplies can be arguably devastating to a disabled person's livelihood; however these issues were commonly overlooked by medical personnel (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 106).

Structural Barriers:

Expensive, unreliable or non-existent public transportation systems such as buses, subways or taxis, also act as a prominent structural barrier in accessing care. Literacy issues, as well as verbal/linguistic and logical/mathematical styles of learning are prominent within medical settings and cause accessibility issues in receiving care. Navigating the hospitals, or understanding one's diagnosis and treatment options may become problematic, for the reason that medical providers have strict schedules which do not allot additional time for personal clarification (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 106). When a disabled person relies on a caregiver, guardian or parent for routine assistance, their personal autonomy and intellectual capabilities often are overlooked by medical personnel. A personal encounter of a disabled man explains how many individual choices are ignored, when stating, "they used to ask my mum or dad. Then they asked me after, but first of all it used to be my mum or dad [even when I was an adult].... I was the one having the operations. [It made me] feel like I'm not there, just I'm there, but, 'oh, well, he can't understand' the procedures anyways" (<u>Roscigno</u> 24).

When specifically analysing the healthcare system within the United States, the research found in Drainoni, Lee-Hood, Tobias, Bachman, Andrew and Maisels text, <u>Cross-Disability Experiences of Barriers to Health-Care Access Consumer Perspectives</u> demonstrates startling personal and cultural limitations to obtaining healthcare. It is not difficult to comprehend that within the privatized medical system of the United States, persons who fall into the lowest socio-economic levels of society face the highest levels of vulnerability and denial when it comes to their financial shortcomings within medical institution. Although the Canadian health care system has many faults, the universality clause in the Canadian Health Act provides all classes, races, genders or ages the right to access care. It could be construed, that within the eyes of many social humanitarians the capitalistic healthcare system of the United States is backwards and neglectful to a large portion of both the disabled and able-bodied populations. The U.S. system of care is fueled by creating profit and financial gain, rather than providing adequate care, inequalities and barriers within healthcare will exist.

Barriers in Receiving Preventative Care:

The lack of knowledge and understanding demonstrated by medical providers such as doctors and nurses when dealing with delicate medical issues was rather alarming. Barbara Altman in her article, "Does Access to Acute Medical Care Imply Access to Preventive Care? A Comparison of Women With and Without Disabilities" suggests that persons with disabilities are more likely to have routine visits with their physician due to increased level of medical need and advice; however, Altman demonstrates an interesting quandary within the medical industry. She found that women with disabilities have increased levels of difficulty when accessing preventative care procedures in comparison to the able-bodied populations. Preventative care procedures include mammograms, papanicolaou smears and healthy dietary practices and advice (Altman 99). Personal experiences provide an exceptional window into citizen and medical personnel encounters that statistics and figures cannot communicate. An example of this was explained by Carol Thomas. She examines the fight of an institutionalised disabled woman who did not feel accounted for within the field of care. She explains, "my first mastectomy was when I was 'in care'. I complained to the doctor about multiple lumps in my breasts, which were dismissed as being neurotic! The [residential] unit's doctor was extremely condescending and patronizing.... I eventually had a biopsy done and was sent back for the result by myself. The verdict came as a shock, and I had to have my breast removed the next day" (Thomas 253). Sadly, often disabled persons concerns are dismissed by medical professionals as exaggerations.

Personal Independence Barriers:

Ingunn Moser author of Socio-technical Practices and Difference: On the Interferences between Disability, Gender, and Class also discusses how persons can be forgotten or overlooked when placed within an institutional setting such as a nursing home. She suggests that nursing homes for younger disabled persons can be dehumanizing and emasculating for men. She suggests that the structure of nursing homes are constructed to house persons who can no long care for themselves and have become fully dependent and reliant on the care of others (Moser 547). This self-realization that one has 'lost' their independence and autonomy can feel demoralizing, especially to youthful individuals. For males specifically, the nursing home provides very limited opportunity to interact with the opposite sex in a normative fashion. Often according to Roscigno, healthcare providers along with common societal perceptions, assume that disabled persons should remain asexual and childless (Roscigno 25)An example of asexualisation was expressed by a disabled woman who was blissfully pregnant, but looked down upon by society and the medical community. "When I was pregnant, my obstetrician called an urologist to consult about the best way to treat these [urinary tract] infections. When my OB told the urologist that I'm quadriplegic, he said, "She's what, and she's having a baby? What is she doing? Why is she doing this?" (Iezzoni, O'Day 67-68). Disability is commonly seen as an obstacle and impediment in living a 'normal' life, many individuals do not perceive that one's disability is something to be overcome, and is simply a conquerable hurdle in the pursuit of living an ordinary life.

Professionalism and Power as a Barrier to Care:

When these negative and inaccurate perceptions circulate within society and the medical field, an individual may feel disrespected, unimportant and vulnerable. These levels of vulnerability are increased when the patient feels consumed within the hierarchal structure of the medical profession. Specialists, surgeons, emergency doctors, family doctors, nurse practitioners, nurses and medical aids all understand that it is their job to stay professional and they must interact with patients according to institutional protocol (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 106). It can be argued that the desire to 'stay professional' in the eyes of medical caregivers can be one of the largest impediments to disabled persons feeling ostracized, barred and dissatisfied with their level of care.

Societal Barriers:

An interesting study was conducted by Fiorilla, Connors, Landry , Loates, Kuzmak, Rutherford, Smith, and Walsh called "Relationality and Reflexivity in Community-based Research" discussed how persons in positions of professional power did not know how to interact appropriately in situations where "disadvantaged" persons opened up emotionally, personally and meaningfully when discussing their differences due to the engrained institutional protocols. The goal of the study was to create inclusion and to generate dialogue between women who commonly would not interact elsewhere in society. A non-restrictive environment was created where people could feel safe to discuss the issues closest to their hearts. Societal barriers towards persons with disabilities because of professionalism will continue to exist if these open and inclusive spaces are not generated within society more frequently. The atmosphere created in these small group settings from personal experience within a community based project was uncanny. When creating my own digital story in coordination with Project Re*Vision, I personally felt overwhelmed by the welcoming, accepting, free and open environment created by the facilitators and participants. It was an atmosphere where anyone could disclose meaningful and personal experiences, as well as, their thoughts and feelings without the fear, judgement or disrespect from others. Community based, inclusive studies are extremely important in creating social change and connections between all classes, genders, ethnicities and economic status.

In another project, "Relationality and Reflexivity," attempted to empower women who were currently using the shelter systems in Vancouver, British Columbia to share their concerns and advocate for their needs through the art of digital story telling (Fiorilla, Connors, Landry , Loates, Kuzmak, Rutherford, Smith, Walsh 1). Educators, students and professionals also collaborated with the women in the hopes of creating a better understanding of homeless issues for women. Within the creation of a safe space, knowledge can be produced and bonds created between strangers who, in turn, often become friends.

The Relationality and Reflexivity study was broken down into individual stories. Natasha, an environmental science student observing the study, explains that when interacting with women of difference, she "did not know what was appropriate or inappropriate to talk about. I had a dichotomy structured in my head where I was a 'privileged' person and the clients were not. This affected what I thought was appropriate for discussion" (Fiorilla, Connors, Landry , Loates, Kuzmak, Rutherford, Smith, Walsh 5). Others explained their attempts to maintain a level of professional and personal disconnection at the beginning of the study. Another women stated, "I felt like I would become too involved in people's situations, and I wanted to help them. However, conducting research forced me to maintain professional relationships with people and not exceed my professional boundaries"(Fiorilla, Connors, Landry, Loates, Kuzmak, Rutherford, Smith, Walsh 5). These questionable 'profession boundaries' may be uncomfortable to navigate for some; however, they are important to acknowledge and disrupt as these boundaries are discursively created within society to separate individuals due to differences.

Community Based Research: Breaking down Social Barriers and Professional Boundaries:

Community projects to create inclusion like this generate new insight and understanding for people like Natasha. She later stated that, "I did not necessarily have to understand their situations and experiences in order to empathise with them". Or Lesley, another researcher, on the project explained that once "I learned to relax and relate to the 'participants' as women and individuals I found that just listening was a great way to begin the engagement process, and I think that many of the women we worked with just wanted to be heard" (Fiorilla, Connors, Landry , Loates, Kuzmak, Rutherford, Smith, Walsh 6). Community based interaction and incorporation is key in the breaking down of barriers commonly found within professional institutions and societal interactions.

These 'professional boundaries' only further reinforce the barriers within medical institutions discussed in Drainoni, Lee-Hood, Tobias, and Bachman's paper. Without social activism and community action, inclusion for disabled persons would not be possible. Negative images and assumptions inaccurately inform society's perceptions of disability and increases able-bodied separation and detachment from disabled persons. This is evident for disabled persons with a physical disability, who are often believed to be "cognitively impaired as well"(Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 106). Medical personnel often reinforce this notion, by segregating disabled patients from general waiting area in doctors' offices (Drainoni, Lee-Hood, Tobias, Bachman, Andrew, Maisels 106). These notions must be disrupted, and arguably the most feasible way to reshape societal understandings in through art-based expression.

Breaking down Barriers: Art Based Expression:

Art-based expression placed disability in the forefront of the able-bodies onlookers' consciousness. Disability art attempts stare-back into the eyes of its oppressor and reverse the gaze and feeling of "otherness" (Eisenhauer 12). Disability art and theater attempts to create "social change through questioning the traditional apparatus of theatrical representation, and by extension, calling attention to the social construction of identities upon which privilege is based... as well as the structure of culture and its divisions of power" (Fox, Lipkin 80). These divisions of power exist within medical institutions as discussed above. Art attempts to make alternate knowledge and perceptions of disability known in a way language could never describe. Jennifer Eisenhauer in her text, "Just Looking and Staring Back: Challenging Ableism through Disability Performance Art" had describes three theatrical performances by three disabled women who effectively upset social notions of disability and creates an experience where the audience questions their own personal interaction with disability and how society shaped disability and difference. One specific artist, Carrie Sandahl is attempting to disrupt the rhetoric created within medical institutions. She titles her performance, The "Reciprocal Gaze" (Eisenhauer 13). She enters the stage wearing a white lab coat, and white pants. Upon the coat in red is an outline of his contorted spine and skeletal structure (Eisenhauer 13). The lab coat is also covered in text. It states her diagnosis, treatment options, past procedures and future outcomes. It also has commonly asked questions like, “are you contagious” and “do you ever dream you were normal”? (Eisenhauer 13). As Sandahl walks across the stage she hands out written letters stating her medical history to all of persons who gaze upon her (Eisenhauer 13).She includes a drawing of her naked body, and where all of her procedural scars are placed including the physician’s names and surgeries performed (Eisenhauer 13). Sandahl has presented herself as a medical chart or case study; as such items are commonly referred to in medical discourses and by doctors. She is a subject, a diagnosis, a cure, and not a vibrant and artistic woman. She invited the audience into her medical and personal life, she expresses that “she is a body to be read” by the world (Eisenhauer 13). She has transformed her body literally into a “textual map and object of exhibition” (Eisenhauer 14); she is attempting to reverse the gaze and disrupt derogatory and dehumanizing techniques when attempting to remain “professional” and detached within a medical setting. Compassion is required in order to no longer have a person’s body be seen as a text, case or diagnosis.

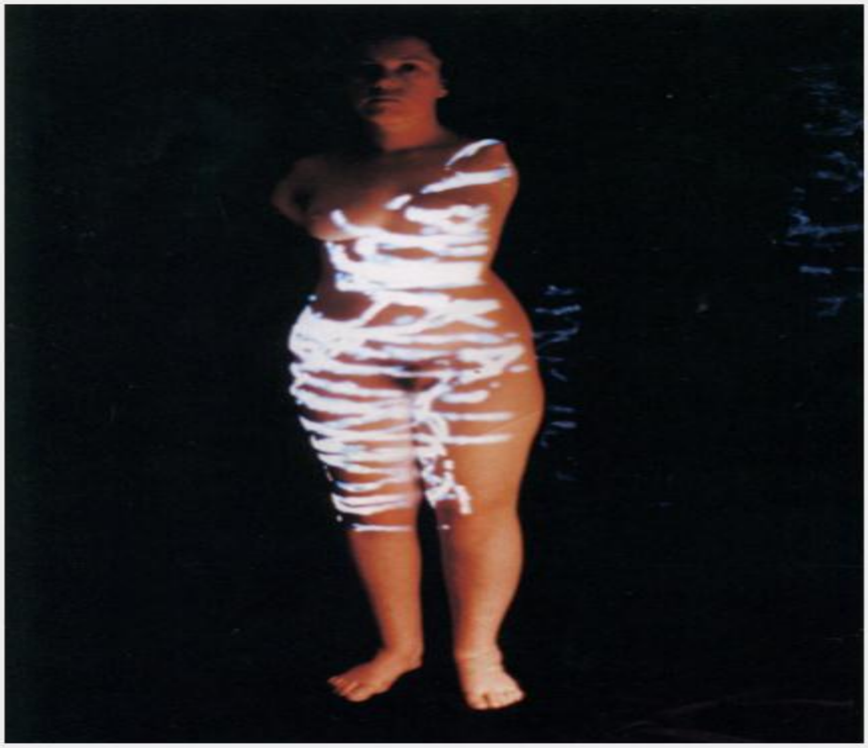
Mary Duffy is another theatrical performer discussed by Eisenhauer. Duffy is attempting to dismantle western ideas of beauty by displaying her naked disabled body on stage as she performs a personal monologue. Duffy was born without any arms and recites this monologue to the audience,

You have words to describe me that I find frightening.
Every time I hear them they are whispered or screamed.
Silently, wordlessly, from the front to the middle-spreads of newspapers
Only you dare to speak them out loud.
I look for them in a dictionary, and I only find some.
The words you use to describe me are
Congenital malformation.
In my child s dictionary I learn that the fist part means "born with."

How many times have I answered that question?
Were you born like that? Or did your mother take them dreadful tablets?
How come I always felt ashamed when answering those big staring eyes and gaping mouths?
Did you have an accident? Or did your mother take them dreadful tablets?
With those big words, those doctors used, they didn’t have any that fitted me properly.
I felt even in the face of such opposition that my body was the way it was supposed to be
That it was right for me
As well as being whole, complete, and functional (...)
Today, I’m winning battles everyday against my own monster? my inner critic
Who has internalized all my childhood oppression
The oppression of constantly trying to be fixed, to be changed, to be made more whole.

(Eisenhauer 15-16).

She explains that she is not a medicalized body in that moment standing naked to be examined and diagnosed. She states, as I stand there “naked and vulnerable, it feels like I am holding up a mirror to your voyeurism and saying, 'So you want to look, do you? I'll give you something to look at” (Eisenhauer 17). She is providing the audience with a cultural marvel of artistic expression in more than one way. Their concepts of beauty and disability are being shaken and reformed, as well, throughout the entire monologue, Duffy’s white naked body is on a platform in front of a black screen, and she resembled the Greek Statue, Venus Di Milo, and indeed is perceived as beautiful (Eisenhauer 16). Reshaping perceptions of beauty and disability are important for adult audiences; however, children should be educated at a young age to understand the importance of community inclusion and how negative stereotypes can drastically harm a person’s perception of themselves.



— Untitled, Mary Duffy (c),from Stories of a Body series, 1990

Curtiss, Ame. "A Small Tale." *Eye to Eye*. The ICP-Bard MFA Blog, 30 Nov. 2009. Web. 17 Apr. 2013.

Educational Institutions: The Creation of the Other

Becoming Visible: Lessons in Disability by Brenda Jo Brueggemann, Linda Feldmeier White, Patricia A. Dunn, Barbara A. Heifferon, and Johnson Cheu, was an excellent source for consulting the societal and institutional discourses surrounding learning or intellectual disabilities within community and education settings. The collaboration of authors expressed concern that the rigid barriers between normal and abnormal persons are strengthening; and that awareness must be brought to this issue within the educational environment. The authors communicate that impairments and disability are not simply personal issue but cultural issues. They state,

> our culture sees disability as a handicap and something wrong with an individual. Disability Studies make a distinction between impairment and disability. Impairment is a physical difference in hearing, vision, mobility or brain function. Disability is more than impairment; disability is what society makes of that impairment in constructing 'disability' as the opposite of something thereby recognized as 'normality', part of a structure that privileges some and oppresses others. (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 372)

Barbara Arneil agrees with the notion that disability is a culturally constructed phenomenon when suggesting that "disability moves away from a medicalized notion of bodily or mental limitations and towards a socially constructed understanding of the interrelationship between the environment and specific bodies and minds it creates a cultural rather than biological meaning to disability" (Wendell 1996, 63).When the concept of disability is socially constructed through discursive methods of power and 'knowledge', societal and institutional attempts to 'help' individuals with disabilities can place these persons in a subordinate position due to the lack of inclusion, understanding, visibility, hierarchical structures and preferred learning styles (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 375).

Learning Disabilities:

Each author focuses on a different element within the journal "Becoming Visible: Lessons in Disability"; all sections were important; however, some held more relevant to the scholarship in comparison to others. Within the first section, Brenda Jo Brueggemann attempts to combat the issue of normality and invisibility among learning disabled individuals. She explains how persons with learning disabilities may “pass as able-bodied persons as they appear before you unclearly marked and fuzzily apparent” (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 371). Disability is generally understood within society as a physical distinction or impairment. When one’s disability is hidden within their body and brain, societal onlookers must conclude for themselves how disability may affect a person’s character. Invisible disabilities such as learning disabilities can be the most difficult to aid and assist. Invisible disabled individuals can be grouped and categorised into what is called “unfit division” which can causes identity confusion, humiliation and shame. Simi Linton author of “Claiming Disability Knowledge and Identity” also discusses the concept of “mainstreaming” and categorizing children at a young age within the educational system as being a fundamental flaw (Fox, Linton 13). Linton explains that the children can become alienated when separated from their able-bodied peers through the use of Special Education or Resource class rooms (Fox, Linton 13). This segregation and separation from one’s peers, friends and understanding of normality can vastly increase the sense of embarrassment and disgrace within the child; which all credible authors within the scholarship of Disability Studies have alluded to within the formation of “otherness” (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 375).

One counter-argument to Brueggemann’s stance which was not discussed within this journal or any other relating research could be the potential empowerment and agency gained from invisible differences, in comparison to persons with visible differences. I, as a person with a learning disability, cannot deny that I have been negatively affected by issues of segregation, isolation, humiliation, shame and identity conflicts due to my disability. This is arguably attributed to how the educational institutions ineffectively labelled, categorised and secluded me as the ‘special child’. However, due to the fact that my disability is not physically visible, I was able to gain a small avenue of agency from this. I effectively and ineffectively attempted to shield myself from the negative perceptions, stereotypes and misconceptions that the gazes of mainstream society placed upon me. This is not to say that because I could hide my difference the insecurities, inadequacies and the constant fear of failure fade; however, it is a personal choice when and if I chose to disclose my difference. My disability has only been disclosed to a select group of people due to the fact I have carried shame associated with my disability for numerous years. As I have matured, my personal acceptance, awareness and understanding have grown and I have come to terms with my difference. Within employment endeavors or within public settings I withhold my difference to ensure I will not be ostracised or excused from partaking in potential opportunities. I do not want a person to make assumptions about my abilities, talents and intellect; I want to prove myself worthy, gain their respect and demonstrate to them I am able to compete with non-disabled persons without being seen with pity or disabled heroism.

Skepticism of Learning Disabilities: Is it all an Act?

The third portion of the text by Patricia Dunn added an important element to the scholarship that was alluded to in other articles but not openly discussed; this is the concept of scepticism and backlash associated with invisible and learning disabilities. The common stereotypes and labels placed on people with learning disabilities such as “stupid, lazy, ‘retarded’, slow and even morally degenerate because of the kinds of errors they make” all appeared within this article and many other texts (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 376). The alternative perspective provided by Dunn suggested that community members were reacting to the ‘special treatment’ being provided to ‘undeserving children’ who are effectively draining the economic resources of the schools (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 377). Some of the quotations provided by Dunn from parents and community members were outlandish and disturbing. These persons were suggesting that children and students with learning disabilities

> are jumping the queue, cutting the line, pushing patient, suffering, ‘average kids’ out of the way and into the shadows while they, waving their learning disabled label and rush to the front to grab an oversized piece of a shrinking pie. ‘Special treatment’ is being successfully posited in this controversy as ‘unfair’ advantage for one group of people: those labeled learning disabled (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 378).

This “smoke and mirrors” argument is very one dimensional as, Susan Wendell and Dustin Galer would agree; very few individuals who have been legally identified as learning impaired advertise their perceived inadequacies (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 378). Wendell discusses how coping mechanisms and tools are essential when dealing with any form of disability and for many individuals there are few perceived societal positives associated with their difference (Wendell 1996, 58).These statements by community members suggest how naive assumptions have created mainstream notions and discourses. Some able-bodied persons are unable to connect with the struggles; challenges and hurdles persons with disabilities must overcome on a daily basis in order to compete, be accepted and perceived as another ‘average kid’. This lack of understanding only increased levels of vulnerability for both men and women within the disabled community. This is why the creation of disability legislation on accessibility for persons with disabilities in schools and society is necessary according to Dunn (Brueggeman, Feldmeier White, Dunn, Heifferon, Cheu 379). Although the legislation is flawed as Dunn and Galer would agree, it is attempting to make a positive difference. The disabled community is attempting to reach a broader audience through the use of art-based expression. These individuals are attempting to help combat these stereotypes by aiming to expand naive person's perceptions of disability and to encompass the struggles and meaning of being perceived as the 'other'.

Arts-Based Expression: Building Inclusion and Fighting the Discourse

Art-based expression is extremely important in creating alternative ways of viewing the world. Art can actively disrupt a person's sense of social order in a positive way (Eisenhauer 15). Artistic statements attempt to awaken the community and engage persons from all ages, genders, races and classed in understanding the lived experiences of persons with disabilities. The multiple forms of art, drama, theater, television, film, song, poetry or canvas art can penetrate a person's understandings of disability in a way completely unique within each member of the audience. That is the simplistic beauty of art. It holds vastly alternative meanings to all of its onlookers. Art can be beautiful, abstract, unique, modern, elegant, grotesque, exotic, repulsive, miss understood, under-rated, overstated or simplistic; but it is personal experience and understanding within oneself that should not be shaped by outside voices or judgments. The multi-dimensional sides to understanding art need to be addressed and used alongside disability activism to demonstrate to communities that disabled persons have unique and positive attributed to contribute to society. Stereotypes, stigmas, categorization and false assumptions about disability need to be reshaped in order to create community inclusion and acceptance. Disability culture has embraced the power of art to emphasize the diversity within the disabled community and the "growing politicization of disabled persons" within global communities (Eisenhauer 7). The disability art movement has fueled the development of many disability artists who create art to contradict negative societal discourses and question the "sociopolitical constructions" of disability and ableism within society (Eisenhauer 9).

Conclusion:

Disabled persons have been perceived as weak, incapable, undesired and unworthy of equal treatment and status in comparison to other able bodied men and women within Western and global societies for many years. These derogatory depictions of persons with a disability from the past have perpetuated into modern society and are commonly used by individuals without question. Many persons are not aware of the power of language, and its ability to belittle individual's character, identity and construct them as the 'other'. Disabled persons rarely have the opportunity to oppose and dispute the dehumanizing language and images used against them. This was until the recent emergence of an artistic disability sub-culture. Within institutional setting such as the medical field or educational system; often professional persons do not recognize that their categorizing terminology can be deconstructive and subordinating, and further the hyper-visibility and disempowerment of disabled persons. For a person to be described as a "case" or "study patient" is demoralizing. Any element of personal connection or identity is removed from this form of labelling and categorization (Wendell 1996, 58). An individual is no longer a distinctive person, with ambitions, pride and enthusiasm; they are a categorised and labelled as an ailment, diagnosis and cure. When professional persons within society refer to disabled persons in a demoralising and demeaning manner, it only magnifies these negative discoursed within society which furthers the societal barriers disabled persons constantly encounter. When a disabled person is wrongfully categorised and marginalised from their peers in the example of the educational system, an identity crisis can occur when attempting to fight back against the incorrect labels and find their own place within society. One way to fight back against the derogatory stereotypes that circulate within society and disrupt them to build inclusions is through art-based expression. Artistic expression covers a multitude of genres such as theater, poetry, drama, literature, film, music and a numerous other forms of individualistic expression. Art is a forum that politicalizes individuals, creates personal agency and question societal protocols within a manner that broad audiences can understand and correspond with. Persons with disabilities are able to collectively unite and fight oppression by generating awareness about the economic, societal and personal levels of inequality, vulnerability and violence many disabled persons encounter daily. This literature review has demonstrated that art-based expression can be used to decrease levels of vulnerability and violence by educating the public in order to reconstruct the mainstream negative stereotypes and the use of restricting, false and categorizing rhetoric within society and institutional structures to create inclusions and acceptance for all community members.

Personal Reflection on the Process

Working with Project Re*vision, the YWCA of Peterborough and my Faculty Supervisor Nadine Changfoot, has truly opened my eyes to disability and difference within my local community and how disability and difference has shaped my life. As mentioned above, I have struggled with my disability for all of my life. As a child I did not understand why I was perceived as different and how society had constructed my body as disabled; all I understood was that I was no longer the same as my peers, and that I was ‘different.’ Difference and disability had created a cloud of shame that consumed my perceptions of my potential intellectual abilities and endeavors as I have aged. I have stayed away from any extracurricular activity that involved reading aloud to avoid embarrassment. It is humiliating to think I am still petrified to partake in a simple board game with my peers. “It’s all in good fun” they would say.

However, I would shake to my core as my turn was called. Teachers were not sympathetic to my anxieties surrounding my disability as a child; I was often forced to read aloud in front of my classmates despite my pleading with teachers to pass me in the rotation. I felt isolated, alone and unintelligent for the majority of my life. I still do not consider my potential intellectual abilities to be “above average.” The medical and educational professionals stated to my parents when I was a child that “I would never be above average.” They suggested that I would continue to struggle my entire life and need assistance performing arbitrary tasks like reading or writing even into my adult years. This board of professionals shattered my ambitions and any form of personal agency I held towards excelling and having a bright and prosperous future. They have no idea how their “diagnosis” has shaped my perceptions of self and identity over the past twenty years. These medical professionals defined and confined my potential into a text that was far from an accurate depiction of who I am.

I rebelled against being isolated and separated into a specialised resource room for children with intellectual disabilities. I avoided receiving help for the fact I feared that along with losing my life ambitions I would lose my friends. Rather quickly, the “help” provided to me was no longer offered and I became the child the educational institution forgot. I struggled through every reading, essay, assignment and class presentation alone. I spent endless hours crying over my seemingly “simple” homework. The time taken to read, write and edit an assignment with my specific difference seems to take two, three or four times longer than the other “average” students. It often seems hopeless and lonesome as people do not understand that reading and writing is an unending battle for me. However, being alone in my fight I have developed ways of coping with my difference on my own terms. I may take longer to produce my final product, it may have “basic” grammatical errors, and only receive an average mark; but I know I put countless hours into the project and I am proud of what I have accomplished.

Project Re*Vison, is my first experience with an organisation that is created to disrupt social stereotypes that surround disability and create positive community inclusion. I have often hid from opportunities to expose myself and my difference due to the embarrassment that has shaped my perceptions of my disability and identity. I was silently reluctant to participate in the workshops they offered to create my own personal digital story with other women who are represented by disability and difference within my community. The opportunity pushed me entirely out of my comfort zone and it was a very emotional and unnerving experience at times. If it was not for Nadine, and the Political Studies course POST 4070Y - Community Engagement Internship offered at Trent University, I may have remained ashamed of my difference for the rest of my life. The workshops were enriching experiences where like individuals were able to come together and converse with a mutual understanding and perception on the world and society. As mentioned above the atmosphere created by the facilitators and participants was completely inclusive, non-judgemental and safe. Unlike any place I have been before.

The digital story process was very empowering for the women involved and has blossomed into a completely separate branch collected from the participants involved, called, Women Building Inclusion. The women and I routinely meet at the YWCA and discuses local issues that are affecting the disabled community. Recently, the main focus is the revamping of the Ontario Disability Support System. Also, they have shown a selection of the disability digital stories created to Peterborough’s local Member of Provincial Parliament, Jeff Leal in order to create a relationship and further community acceptance and inclusion for persons with disabilities. After working with these women and writing this report, I can see the impact art based expression can make in a person’s life, providing them hope and courage to become a self advocate for change. When starting the process of making my own digital story, I did not understand the power film held to reach an audience and individuals in a way unlike other mediums of knowledge. At the time, I did not comprehend the power my short self reflexive film would have on my life and potentially the life of others; I effectively stared back at the educational system that belittled and demeaned me for the majority of my youth. My film empowered me to accept my difference and see that I am not alone in my fight.

The “Mobilizing New Meanings of Disability and Difference” Project has become more than I could have ever anticipated. It has reinvigorated within myself and the other participants the fact that our capabilities in life are not limited. We can strive to excel within society and be seen by societal onlookers as more then disabled or different. The world is filled with endless possibilities for disabled persons if they are willing to become liberated, politicised and self advocates to dismantle the negative societal stereotypes; and fight for equal opportunities, to participate, be heard and be seen as equal, proud, strong and important contributors to society.

I believe the largest recommendation for making positive change is to educate the younger generations. In doing so, it can effectively stop the stereotypes and stigmas within society before these notions become imprinted in young minds at “truths”. Digital story making and telling would be an excellent way to reach children on a level they would understand and embrace. If showing digital stories in schools and or allowing children and teens to make their own digital stories were possible, it could help create a common understanding and acceptance of persons for their differences would hopefully become universal and positive social change could occur.

Mobilizing New Meanings of Disability and Difference Poster:

The image below was a poster I produced to attend the “Community Innovation Forum: Knowledge and Talent in Action 2013” in Peterborough Ontario. It is an event for students who have created a community bases education project from both Trent University and Fleming collage in Peterborough to showcase their work and educate the public. It was a daylong event with a variety of speakers, panel discussions and awards presented to admirable projects. My project and poster received the runner up positions for the Social Innovation Award. Both Trent and Fleming students are analysed to see if their projects represented an innovative way of addressing a specific issue that affects a marginalised group of the community. The project must have numerous avenues of impact to create valuable social change within the local and global community.

Creating the poster was a unique way all persons were able to convey what they have learned when researching and constructing their projects through a medium that is embraced and easily understood by the public. Other students may not consider their posters “art” in the traditional sense, but after creating my literature review my understanding of art, and artistic expression have change. My poster used language, images, facts and quotes to entice their audience and spectators in a way words on their own cannot. When creating the poster I tried to think of the best way to articulate the important messages of the project in an interesting and versatile way. Although it may not fit into the traditional understandings of art; I consider my poster a small form of artistic expression that hopefully reached its viewing audience on a deeper level of understanding.

Mobilizing New Meanings of Disability and Difference

•Student Researcher: Amber Flynn
•Faculty Host : Professor Nadine Changfoot. Political Studies 4070
•Community Host : Joëlle Favreau and the YWCA of Peterborough Victoria and Halliburton

Purpose of the project:

❖ For women with disability and healthcare providers to make self reflexive Digital Stories through art-based expression

❖ **Why:** To shift the common misconceptions of disability and difference in order to advance health care, educational and community inclusion for women with disabilities

Methodologies:

❖Digital Story workshop with disabled women and healthcare providers
❖Literature review
❖Attendance to Re-Vision Forum and Retreat

Findings:

❖Total inclusion for disabled persons within community setting is possible
❖Societal stereotypes, barriers and perceptions must be broken down to obtain complete inclusion
❖Societal change is possible through public education
❖Arts bases research and expression provides alternative ways to create societal change and understanding

Digital Storytelling: Everyone has a story:

❖ Short self reflective 2-3 minute films using images, music, narratives and one's own voice

Provides :

❖The ability to creatively capture and express ones self
❖A description of how a person felt in that specific moment in time.
❖Emotional empowerment
❖ Deepen the audiences understanding and connection to another individual's personal experiences and stories

The Literature Review Discusses:

❖The concept of identity.
❖How common stereotypes and stigmas create a negative image and self identity for disabled persons.
❖How stereotypes create vulnerability and relate to violence experienced by disabled persons.
❖How art based research such as digital stories and theater productions combat these stereotypes
❖How the medical profession and educational environment can act as barriers in receiving proper care
❖How effective change is possible to create inclusion

"Everyone can alter their lives, by altering their attitudes"
Andrea Dodsworth – Digital Story Participant -2012

Special Thanks to: Trent Centre for Community-Based Education TRENT UNIVERSITY YWCA PROJECT RE-VISION

Work Cited:

Altman, B. M. "Does Access to Acute Medical Care Imply Access to Preventive Care?: A Comparison of Women With and Without Disabilities." *Journal of Disability Policy Studies* 8.1-2 (1997): 99-125. *Sage Journal*. Web. 9 Oct. 2012.

Arneil, Barbara. "Disability and the Politics of Self-Image in Modern Thought." *Political Theory* 37.2 (2009): 218-42.

Arneil, Barbara. "Recognizing Difference/Achieving Equality: Multiculturalism and Gender Justice." *2008 Expert Roundtable on Canada's Experience with Pluralism* (2008): 1-22. *Global Center for Pluralism*. 2008. Web. 11 Oct. 2012. <www.pluralism.ca>.

Brueggeman, Brenda J., Linda Feldmeier White, Patricia A. Dunn, Barbara A. Heifferon, and Johnson Cheu. *Becoming Visible: Lessons in Disability.* Rep. 3rd ed. Vol. 53. Atlanta: n.p., 2001. Web. <http://epcc1301.pbworks.com/w/file/fetch/46964126/Problematizing%20Essay%20-%20Lessons%20in%20Disability.pdf>

Clifford, Cassandra. "International Human Rights Day." *Foreign Policy Blog*. Foreign Policy Association, 10 Dec. 2010. Web. 17. Feb. 2013.

Crew, Robert. "Entertainment." *Thestar.com*. The Toronto Star, 2013. Web. 01 Apr. 2013.

Department of Economic and Social Affairs. "Rights and Dignity of Persons with Disabilities." *UN News Center*. UN, n.d. Web. 07 Jan. 2013.

Drainoni, M.-L., E. Lee-Hood, C. Tobias, S. S. Bachman, J. Andrew, and L. Maisels. "Cross-Disability Experiences of Barriers to Health-Care Access: Consumer Perspectives." *Journal of Disability Policy Studies* 17.2 (2006): 101-15. Web. 11 Oct. 2012.

Eisenhauer, Jennifer. "Just Looking and Staring Back: Challenging Ableism through Disability Performance Art." *Studies in Art Education* 49.1 (2007): 7-22. *JSTOR*. Web. 13 Nov. 2012. <http://www.jstor.org/stable/25475851>.

Ferrari, M. (2010). My journey through my Qualifying Exam using reflexivity and resonant text: 'what I know'; 'how I know it'; and 'how I experience it'. *Reflective Practice*, *11*(2), 217-230.

Fiorilla. L, Connors. A, Landry , Loates. A, Kuzmak. N, Rutherford. G, Smith. L, and Walsh. C."Relationality and Reflexivity in Community-based Research: Reflections from the Field." *Teaching and Learning Journal* (2009): n. pag. *Community-Based Research Reflections*. Nov. 2009. Web. 10 Oct. 2012. <http://kwantlen.ca/TD/TD.3.2/TD.3.2_Walsh_etal_Community-Based_Research_Reflections.pdf>.

Fox, Ann M., and Joan Lipkin. "Res(Crip)ting Feminist Theater Through Disability Theater: Selections from the DisAbility Project." *NWSA Journal* 14.3 (2002): 77-98. *JSTOR*. Web. 04 Oct. 2012. <http://www.jstor.org/stable/4316925 .>.

Galarneau, Diane. "Employment Among the Disabled." *Employment among the Disabled*. Statistics Canada, 29 Mar. 2010. Web. 03 Mar. 2013.

Galer, Dustin. "Disability and Social Change: Private Lives and Public Policies." *Disability & Society Publication* 27.2 (2012): 299-301. Print.

Iezzoni, L. I., & O'Day, B. *More than ramps: A guide to improving health care quality and access for people with disabilities*. New York, NY: Oxford University Press. 2006

Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York: New York UP, 1998. Print.

Moser, Ingunn. "Sociotechnical Practices and Difference: On the Interferences between Disability, Gender, and Class." *Science, Technology & Human Values* 31.5 (2006): 537-64. *Sage Publishing*. Web. 19 Feb. 2013. <http://www.jstor.org/stable/29733956>.

Roscigno, Cecelia. "Challenging Nurses' Cultural Competence of Disability to Improve Interpersonal Interactions." *Journal of Neuroscience Nursing* 45.1 (2013): 21-26.*Gale Datebase*. Web. 12 Mar. 2013. <http://dx.doi.org.cat1.lib.trentu.ca:8080/10.1097/JNN.0b013e318275623b>.

Sherwood, Katherine. "Art, Medicine, and Disability." *Radical History Review* 2006.94 (2006): 191-96. Print. Thomas, Carol. "Medicine, Gender, And Disability: Disabled Women's Health Care Encounters." *Health Care for Women International* 22.3 (2001): 245-62. *Gale Virtual Reference Library*. Web. 12 Mar. 2013.

Van Daalen-Smith, Cheryl. "My Mom Was My Left Arm: The Lived Experience of Ableism for Girls with Spina Bifida." *Contemporary Nurse* 23.2 (2006): 262-73. Print.

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

Yuval-Davis, Nira. "Belonging and the Politics of Belonging." *Patterns of Prejudice* 40.3 (2006): 197-214. *Sage*. Web. 07 Dec. 2012. <http://www.uk.sagepub.com/books/Book229032>