Spina Bifida: Front to Back

Teaching Resource Guide

Exhibition Overview

Spina Bifida: Front to Back
Steve Kean

Jan 9 - Jan 27, 2017

Spina Bifida: Front to Back provides the Humber community with an educational opportunity to increase their awareness about people with disabilities and issues around accessibility. The exhibition contains several pairs of portraits of people living with spina bifida. In one photograph we see their front, clothed and in colour, and in the second photograph we see their back, nude and in black and white. Visitors will see them as people first; people whose lives have meaning and are beautiful.

Body image remains a relevant topic in the context of disability. Spina bifida often results in the necessity of using a wheelchair. People look down on those with spina bifida literally and figuratively. They have historically suffered great indignity, even for sake of medical education. Being the subject of treatment and learning is an experience many of those with spina bifida share.

Photographer Steve Kean is a disabled artist who has spina bifida. For the first time in his artistic practice he is examining how people like him who live with this condition view themselves and seek to claim their power and beauty. Front to Back is a true collaboration between Kean and those he photographed. It is a path to a sense of dignity and control over what happens to those with spina bifida. These portraits show spina bifida as a beautiful part of how they inhabit their bodies and shape their lives.

This exhibition is presented by Tangled Arts and sponsored by Humber's Centre for Human Rights, Equity & Diversity.

How to Use This Guide

Use this resource to help prepare your students for the exhibition and to extend the learning back into the classroom. This guide contains a selection of portrait pairings on display in the exhibit, each accompanied by a brief explanation of a relevant disability topic and discussion prompt to aid in unpacking that piece. They are organized under the following headings: **Photographing Disability**, **Medical vs. Social Model of Disability**, **Disability & Identity**, and **From Ableism to Ally**. The section titled **Doing Disability Ally Work** is a community resource prepared by disability rights activists (it can be downloaded as a separate flyer from eliclare.com).

Photographing Disability

DISCUSSION PROMPT

What is the difference between positive representation and exploitation? Consider who is being represented and by whom.

BACKGROUND

Spina bifida: The literal translation of spina bifida is split spine. The condition occurs when the spinal column does not close all the way in the womb. Complications from spina bifida range from minor physical problems to severe mental and physical disabilities.

Recommended Language: It is acceptable to describe a person as "someone with spina bifida" or "someone living with spina bifida."

"The back portrait is about showing something that isn't seen – the source of the disability, the source of the pain, the source of all the fear and frustration."

– STEVEN KEAN, PHOTOGRAPHER

Photographer Steve Kean is a disabled artist who has spina bifida. His photographs examine how people like him who live with this condition view themselves and seek to claim their power and beauty. Front to Back is a true collaboration between Kean and those he photographed. It is a path to a sense of dignity and control over what happens to those with spina bifida. These portraits show spina bifida as a beautiful part of how they inhabit their bodies and shape their lives.

"My scars were like a road map of my journey living with spina bifida."

Shauna: When Steve first suggested this I was curious, but not hesitant at all. My scars are part of me, not something I worry about. Actually it was more challenging to have my face photographed than my back… As we got into it, I realized my scars were like a road map of my journey living with spina bifida. I am proud of my participation in this project.

Medical vs. Social Model of Disability

DISCUSSION PROMPT

It is society that disables people.

BACKGROUND

The medical model of disability views disability as a 'problem' that belongs to the disabled individual. Under this model of disability, disabled people's inability to join in society is seen as a direct result of having an impairment and not as the result of features of our society which can be changed.

The social model of disability, in contrast, draws on the idea that it is society that disables people, through designing everything to meet the needs of the majority of people who are not disabled.

The social model of disability makes the important distinction between 'impairment' and 'disability':

Impairment: An injury, illness, or congenital condition that causes or is likely to cause a long-term effect on physical appearance and/or limitation of function within the individual that differs from the commonplace.

Disability: The loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.

Example: if a wheelchair user is unable to get into a building because of some steps, the medical model would suggest that this is because of the wheelchair, rather than the steps. The social model of disability would see the steps as the disabling barrier.

> *"A person with a disability is just as normal as the next person."*

Michelle: When Steve asked if I would be part of this project, I wasn't sure. I needed to think about the world seeing my body...I didn't know what to expect, but when I saw the images they made me feel beautiful...I hope lots of people have a chance to see them, and see that a person with a disability is just as normal as the next person.

Disability and Identity

Discuss reasons why someone may or may not want to identify their disability. Let this open into a broader discussion about stigma and ways to overcome it.

BACKGROUND

Invisible disabilities: The majority of disabled people have disabilities or chronic illnesses that are invisible or hidden. Although many in the general public associate disability only with people using wheelchairs or white canes or who are missing limbs, more people have conditions that can't be seen but are defined as disabilities. For example, many mental health and chronic health conditions can be considered invisible disabilities depending on their severity and impact on daily living.

Disability and disabled generally describe functional limitations that affect one or more of the major life activities, including walking, lifting, learning, breathing, etc.

Recommended Language: Do not use the term invisible disability without asking the person being discussed about their preference.

Some prefer to use "people-first" language, which refers to the person first and the disability second. For example: "The writer, who has a disability." Others may prefer "identity-first" language because they consider their disabilities to be inseparable parts of who they are. They embrace the terms autistic or Deaf or blind or disabled as their identity. Always ask for a person's preferred terminology.

Disability and people who have disabilities are not monolithic. Avoid referring to "the disabled" in the same way that you would avoid referring to "the Asians" or "the Jews." Instead, consider using such terms as "the disability community."

"He's capturing what the world doesn't normally get to see."
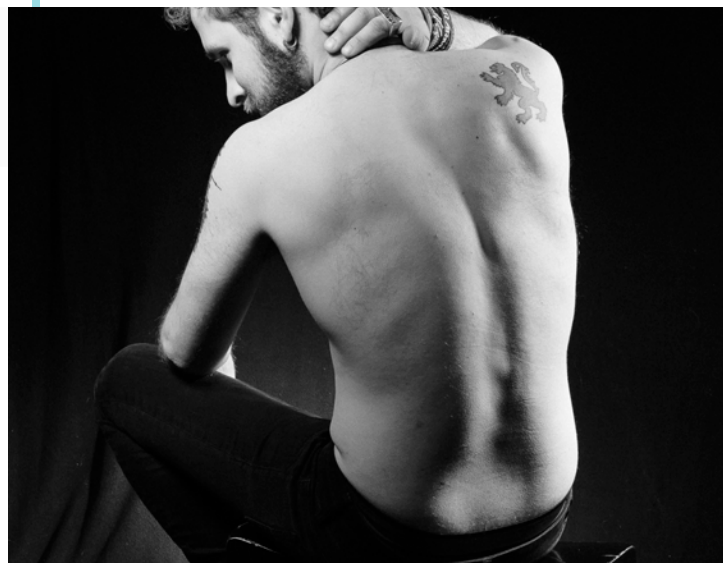
Danny: I'm a singer through and through. When Steve approached me about the project, I didn't hesitate whatsoever. He's capturing a different element with this project, what the world doesn't normally get to see. Just like the theatre, behind the scenes, it's the backbone, the foundation of what someone achieves.

From Ableism to Ally

DISCUSSION PROMPT

What are some examples of things people say or do in daily life that marginalize or stigmatize those who live with disabilities, and how can we work to eliminate it?

BACKGROUND

Ableism is a form of discrimination or prejudice against individuals with physical, mental, or developmental disabilities. It is characterized by the belief that these individuals need to be fixed or cannot function as full members of society.

As a result of these assumptions, individuals with disabilities are commonly viewed as being abnormal rather than as members of a distinct minority community. This interpretation of disability as a defect rather than a dimension of difference is the root of ableist acts that cause far too many to feel marginalized, discriminated against and ultimately devalued in this society.

Ally: Disabled people are everywhere, and yet are mostly invisible to the nondisabled world. Everyone grew up learning stereotypes about disabled people. Some of these stereotypes are negative ("helpless," "dependent," "useless"). Others seem positive but are just as limiting ("cheerful," "inspiring," "brave"). In order to end ableism, nondisabled people need to learn how to do disability ally work.

It is the role of the ally to educate oneself and others, to take leadership from disabled people and work in their own communities towards creating change.

"In difference lies strength."

Laurence: I was really happy to have the opportunity to participate in Steve's project. I did not hesitate one second before agreeing to be a part of Front to Back. I saw a beautiful way of showing spina bifida. In difference lies strength. I did not think putting the focus on my scar and my deformity would give such great pictures and that what comes out of these pictures the most is the beauty of my personality.

Doing Disability Ally Work

RESPECT

- **Recognize** that disabled people are inherently worthwhile.
- **Listen** to disabled people's stories, experiences, and perspectives.
- **Understand** that having a disability does not make our lives any more inspirational, pitiful or tragic than yours. Our disabilities are ordinary and familiar parts of who we are.
- **Ask before you offer help** to a disabled person. What you assume is helpful may not be. Start with a friendly but non-intrusive question: "Can I provide assistance?" or "Can I get that for you?" Be aware that your offer may not be accepted. Disabled people are the experts about our own lives and what we need.
- **Don't ask** intrusive questions, however well-intentioned. Because of how disabled people are separated from society, many of us deal with daily curiosity about our bodies, minds, and lives. This can be irritating, exhausting, and demeaning.
- **Challenge** your own assumptions. Many people have disabilities that might not be apparent to you. Everyone has a right to request and use the access they need without being criticized or questioned.
- **Ignore** service dogs while they're working. Don't pet, feed, or interact with them.

LANGUAGE

- **Don't use** the words "cripple," "defect," "spastic," "lame," "retard," and "crazy." These words have long been used to bully and oppress disabled people. You may hear disabled people calling each other "crip" or "gimp," This is "insider" language, akin to LGBT people calling each other "queer," but isn't appropriate language for non-disabled people to use.
- **Use** the phrase "disabled people" or "people with disabilities."
- When you hear other people use ableist language, **take the opportunity** to challenge and educate.
- **Don't ask,** "What's wrong with you?" Disabled people have many different relationships with our bodies and minds. Don't assume you know what's right or wrong.

ACCESS

- **Work to create** accessibility in your community, workplace, and place of worship. Ramps and elevators are vital, but access doesn't stop there.
- **Access means** creating an inclusive and welcoming space for all members of your community:
  - **Ensure** that people with mobility aids and/or personal attendants can use the bathrooms.
  - **Minimize** the presence of scented products and other triggers for people with chemical sensitivities with the goal of creating scent-free space.
  - **Offer** printed materials in alternative formats, such as Braille, large print, and audio.
  - **Provide** sign language interpreters and real time captioning.
  - **Choose** locations for community events near public transportation.
  - **Offer** sliding scales at events that cost money.
  - **This is not an exhaustive list, only a starting place.**
- **Understand** that no single accommodation will work for all disabled people. One solution doesn't fit all, but increased access does benefit everyone.
- **Take your lead** from disabled people. We know what works best for us.
- **Be creative.** Don't use lack of money as an excuse not to create access.

ACTIVISM

- **Educate yourself.** Read about the disability rights movement. Attend disability culture events.
- **Recruit** members of the disability community to leadership positions within your organizations.
- **Confront** disability stereotypes and oppression—ableism—wherever you encounter them.
- **Integrate** disability issues into your understanding of racism, classism, sexism, homophobia, and transphobia. These systems of oppression are all interrelated.

A community resource created by disability rights activists. For more info: **eli@eliclare.com** *or* **www.eliclare.com**

Exhibition Contributors

Steve Kean is a photographer living in Toronto. He recently completed a Masterclass where he continued his work that focuses on how people with disabilities inhabit their bodies and how it may differ from everyone else. Influenced by the Henri Cartier-Bresson and W. Eugene Smith, Steve seeks to capture the moment(s) that can define his subjects and their place in society.
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Tangled Art + Disability is boldly redefining how the world experiences art and those who create it. We are a not for profit art + disability organization dedicated to connecting professional and emerging artists, the arts community and a diverse public through creative passion and artistic excellence. Our mandate is to support Deaf, Mad and disability-identified artists, to cultivate Deaf, Mad and disability arts in Canada, and to enhance access to the arts for artists and audiences of all abilities.
http://tangledarts.org/

Humber's Centre for Human Rights, Equity & Diversity
The Centre's initiatives integrate the complex and often contradictory ways that socially constructed identities intersect and interlock. As such, initiatives extend beyond binaries such as male/female, black/white, gay/straight, able/disabled to include multiple layers of identity that are experienced simultaneously. This intersectional and integrative approach, grounded in a practice of care, is woven throughout all of the Centre's services.
http://hrs.humber.ca/human-rights-equity-diversity.html