FACING DIFFERENCES

FACING DIFFERENCES:

AN ANALYSIS OF MEDIA REPRESENTATION OF FACIAL DIFFERENCE

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Abstract

The purpose of this paper is to explore how the mainstream media in Western society represents facial difference, and in turn, how such representations impact individuals who identify as having a facial difference. The study is based on findings from a four-hour focus group with individuals (aged 18-30) who identify as having a facial difference. The data is interpreted and discussed using a critical framework; specifically, Critical Disability Theory.

The subsequent findings indicate that how the media represents facial difference has a significantly negative impact on individuals with a facial difference, in terms of their development of self-esteem and self-worth. It was also apparent from this study that the media plays a large role in the development and maintenance of one's "understanding" of facial difference.

Major themes emerging from this research include: How individuals feel 'othered' because of their facial difference; How language plays a role in maintaining stereotypes of "difference"; How pre-natal testing for "birth defects" can lead to termination of life, and how this related to eugenics; How powerful and pervasive messages from the media can be in relation to physical difference; and how subsequent stigmas impact individuals with facial difference.

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Introduction

On a cold January morning in a hospital full of newborns, a girl was born who stood out from the rest. The mother was told by her doctor, "You have a beautiful girl, but she has a cleft lip". They questioned the mom if this condition was hereditary, but after calling her husband and her mother from the hospital room where she rested on her own, it was determined there was no history of cleft lip and palate on either side of their family. If the reader could envision for a moment: a tiny face with a tiny mouth that was without a palate - the roof of the mouth was not there. In addition, there was a split in the baby's upper gum, and no upper lip to hold its nose in the symmetrical centre of her face.

The nurses were unsure how to proceed with feeding this baby, but eventually the mom utilized a lamb's nipple attachment on a bottle to drip milk into the baby's mouth, thus eliminating the impossible task of asking the baby to suck on the bottle. The baby had an appliance inserted into her mouth which acted as a palate and without which she would have no chance of eating. This appliance had strings which came out of her mouth and were taped to her cheek. Alongside this, the baby had two rubber rings on each cheek that attached in the middle which encased the small face and prevented the cleft from stretching or tearing. Strangers on the street wanted to know why there was string on this baby's face; a few even pulled the entire appliance out for fear that the baby was choking on string.

When, by seven weeks of age the baby had gained enough weight to successfully manage surgery, she was able to have her lip repaired so that it was finally closed. As a

result, it was less obvious to strangers that there was anything "different" with this child, and the comments to the mother that it was "terrible" to have a child like hers ceased. When conversations did arise about the baby's condition, many people would offer support by noting that there were famous people with cleft lip and palate, as if to comfort this mom by suggesting that this baby was not entirely hopeless.

Having been born with the congenital 'birth defect" known as *a uni-lateral cleft-lip and palate*, I have lived my life avoiding mirrors, and negatively comparing myself to the images of beauty that I saw in movies, television, and advertisements. My personal experience with being "different" has led me to an interest in analyzing the role of media in representing physical difference and disability. Specifically, this research has sought to examine how individuals who identify as having a facial difference view current representations of facial difference in mainstream media and what they understand to be the impacts of such on their own lives.

In this day and age, we are inundated with advertisements, movies, television shows, and literature at a rate and with more influence than ever before (Kilbourne, 1999) and we live in a world where the media has substantial impact on individuals' understanding of difference (Safran, 2001). As such, exploring the media's representation of facial difference is an important topic to address, as it is necessary to understand what (if any) impact and influence the media has historically had on people with facial differences. And further, to investigate what part the media might play in maintaining particular societal views about facial difference - both in terms of how media may or may

not affect the feelings of self-worth of people with facial difference, but also, how these individuals view their position in society based on how others see and treat them.

The broader research literature on the media and physical disability reveals that it is now indisputable that Western society has had a long-standing fear of and misgivings about difference. In fact, those with a physical disability have historically been pushed to the fringe of society and given second-class citizenship status (Phillips, 1990). As a result, many individuals have been unable to contribute to the creation or control of the messages and representations that have been generated for the masses by which an understanding of disability is formed. Many people develop an understanding of difference, in part, through the information they receive from mass media (Safran, 2001); an unconscious process that often starts at a young age. Deconstructing the larger social structures that have shaped and perpetuated societal understandings of physical difference is necessary in order to interrupt and interrogate the constant flood of disability imagery that enters our minds, often without much question or thought.

This thesis centres itself in critical and interpretive research to address notions of use of language in the media, inclusion and exclusion based on appearance, as well as how current representations are understood and accepted by a large majority of people. The aforementioned will be discussed, as experienced by a small group of people with facial difference, in response to media representations of people identified as having facial difference. It is necessary to point out that my social location as the researcher with a facial difference does, to some extent, shape this research study – both the processes of designing and conducting the research, and also the interpretations of the results. It has

also led me to the belief that participatory research methods were required to (hopefully) create a more relevant knowledge base about this topic. Nevertheless, it has been challenging to manage my own feelings and biases as I worked with the data.

Throughout this thesis, I will be using the term "physical difference" to represent what others may understand as "deformity", "defect", or "disability". The term "physical disability" encompasses a broad range of conditions, and interpretations that are too vast to explore here. Briefly, my understanding is that "physical disability" includes a wide range of bodily characteristics (such as scars, birthmarks, and or specific congenital birth conditions) that are seen as "different" from what we typically understand as "normal" (Turner & Stagg, 2006) and, as a result, includes facial differences. It must be noted that I will be calling on the research literature on physical difference to enhance this discussion of facial difference because there is a paucity of research pertaining to how facial difference, specifically, is represented in the media.

To situate the reader within the context of how I came to the decision to undertake this issue in my Master's thesis, a review of the broader literature pertaining to the representation of physical difference in the media, as well as the more particular literature on media representation of facial difference, will be provided. A discussion of the research that has been done on self-esteem for those with a facial difference will conclude the literature review portion of this work. This will be followed by an explanation of the methodologies guiding this research, after which I will provide a detailed analysis of the data. The thesis will conclude with a discussion about what has been brought up from the research, as well as how all of this pertains to or has implications for the social work

profession. The hope for this research is to bring awareness to the following questions:

does the media play a role in the development and or maintenance of negative stereotypes

and stigma of facial difference? What impact have current representations of facial

difference had on young people who identify themselves as having a facial difference?

And what then might the profession of social work's responsibility be to attend to such?

Literature Review

There are three areas of research literature that are pertinent to the topic of media representation and facial difference. In this review, I will explore what the literature tells us about societal understandings of "physical difference"; the role of public media in our understanding of physical difference, and what is known about self-esteem of those with facial differences. It is important to note that to date, the majority of research addresses physical differences in the media; a reality that supports the need for research which specifically explores facial difference and its relationship with the media.

How Does Our Society "See" Physical Difference?

A brief discussion about the historical and contemporary relationship that Western society has had with physical difference (including facial difference) is necessary to support the reader's understanding and appreciation of how the damaging ways physical difference has tended to be seen and understood. Funk (1987) explains that the current policies and practices that pertain to individuals with disabilities are "based on unfounded, outmoded stereotypes and perceptions deeply rooted in prejudices…" (p. 7) and largely see these individuals as "unable or unwilling" to contribute to society (p.9). References to individuals with disabilities can be seen in some very early historical documentation (Fudge Schormans, 2005). For example, early Christianity viewed disability as having its origin as demonic or divine, and therefore saw these individuals as soulless, or not human (Ingstad, 1995; Reynolds Whyte, 1995; Winzer, 1997).

Moreover, Pointon and Davies (1997) suggest that the way in which difference and disability is seen in contemporary society is connected to centuries of "knowing" about "difference". These authors explain that throughout many historical eras, disability has been understood as something to signify sin. In the Old Testament we see that it does not allow the "blind man or the lame or he who hath a flat nose…to approach to offer the bread of his God" and "No man who has any defect may come near: no man who is blind or lame, disfigured or deformed" (Leviticus, 21:18; King James Version). Throughout the medieval period, individuals with disabilities were subjected to attack and persecution, because they were believed to be unable to know God (Fudge Schormans, 2005; p. 27).

While society's relationship with, and understanding of difference has changed over time, there is still bias, and therefore, still cause for concern. Pothier and Devlin (2006) examine how Western society's response to "difference" has shifted over the last few centuries between charity and welfarism, however, neither has been an appropriate response to individuals so labelled as 'different'. In particular, the media environment in which physical difference is emphasized is generally associated with charity or medical advertising (Barnes & Mercer, 2003; Covey, 1998). An example would be how we might more often see someone with a physical disability in an advertisement for a wheelchair, as opposed to in an advertisement for Chanel perfume (Parashar & Devanthan, 2006).

The Media's Take on Physical Difference

The literature suggests that the media (including television, movies, and advertisements) has profoundly shaped society's conceptualization of physical difference. Jaeger and Bowman (2005) point out that the information people receive through advertisements, television, and movies accounts for a significant percentage of what we "know" about people, events, or places. The literature strongly supports the notion that the mass media is a key player in the creation and maintenance of societal understandings of physical difference (Auslander & Gold, 1999). It has become clear that the media uses particular frames when representing physical difference that call on the use of certain words or images that reinforce inaccurate judgements and stereotypes (Haller & Rahn, 2006). Through this selection of certain words or images over others, the media can ensure certain messages about physical difference are made more prominent and thus more memorable to the audience. This concept of framing is useful to understand how perceptions and discourses are created – and reinforced – by way of the media.

Safran (2001) points out that popular media formats (for example, movies) likely will always have a significant impact on public perceptions of difference because they do more than just entertain -- they provide information. An appreciation of the notion of a citizen regime is useful to posit the place of individuals with physical differences within our society and the role of the media in this positioning. Dobrowolsky and Jensen explain how "A citizen regime encodes within it a paradigmatic representation of identities, of the national as well as the model citizen, and second-class citizen, and the noncitizen" (2004, p. 156). Phillips (1990) point out that through media imagery, individuals with

"differences" are seen as failing to meet certain standards, and are automatically re-classed as "irregulars, seconds, damaged goods" (p. 850). Similar to Covey's (1998) argument, these authors believe that media representations of physical disability thus plays a role in establishing and maintaining the long-standing boundaries around who will be socially included and who will be excluded. For example, Phillips (2001) explains that "In some instances, photographic image and accompanying text combine to reinforce the notion of persons with disabilities as helpless and needy people" (p. 195), meaning, we are continually being exposed (overtly or subtly) to certain representations of physical difference which inevitably leads the viewer to see an individual with a physical difference as 'lesser than' an individual without such a "difference".

Funk (1987) argues that the (typically able-bodied) decision makers in Western society do not value the notion of integration as it relates to the inclusion and participation of those seen as having "differences". Given that denigrating attitudes, prejudices, and marginalization towards individuals with physical differences have existed for centuries, the hegemonic understanding of this group remains steadfast and something that many do not think needs to be questioned. Funk (1987) blames this on "the overriding influence of persisting images of disabled people as deviant, incompetent, unhealthy objects of fear who are perpetually dependent upon the welfare and charity of others" (p. 23). Sadly, the popular media plays a role in establishing and re-enforcing this ubiquitous notion that to be "different" is to be "wrong" and the result is a stronghold of social attitudes and behaviours towards "difference".

Indeed, Covey (1998), alongside Parashar and Deventhan (2006) argue that the media has not only been responsible for initiating, but also for perpetuating numerous stereotypes of physical difference, such as depicting "charity appeals" as reliant on the "pity and assistance of persons without disability", and that individuals with a physical difference are unable to engage in "routine activities" (p. 18). There have been a number of studies done to analyze the roles and appearances of characters with a physical "difference" in the media. Barnes and Mercer (2003) explain how "Stereotypical and distorted representations of people with physical impairments have been standard fare in cinema film" (p. 96). In addition, Hartnett (2000) argues that characters with physical differences are used for dramatic effect, as opposed to representing a real person who is fully-formed and "typical" or "normal". As well, a number of researchers suggest that in literary and film media, people with physical differences are put into a number of common categories: someone to pity, or someone to fear (Covey, 1998; Jaeger & Bowman, 2005; Franks, 2001; Funk, 1987; Longmore, 1987).

Several researchers have noted that characters that have physical disabilities in popular books tend to fall into the category of "demonic cripple or charity cripple" (Covey, 1998; p. 11). In *Moby Dick,* Captain Ahab is depicted as vengeful and evil as a result of losing his leg. Conversely, Tiny Tim has tugged heartstrings worldwide, and continually creates feelings of pity or empathy for the reader/viewer of *The Christmas Carol* (in books, movies, or plays). Covey (1998) explains that these characters have remained steadfast in our culture - plaguing this population for centuries - and play a role in reinforcing stereotypes and prejudice towards those with a physical "difference". As

these values continue to permeate our movies and literature, they often send messages that become unconsciously accepted.

Dahl (1993) emphasizes that it is often seen that in media representations physical differences tend to symbolize evil or monstrous behaviour. Dahl notes that one can look also to other literary and film characters such as The Hunchback of Notre Dame, Dr. Frankenstein's 'monster' creation, Captain Hook, Long John Silver, and Mr. Hyde (to mention only a few) who were all understood as villainous in relation to their physical difference. Synnott (2006) suggests that this tradition stems back to Homer's *Odyssey* and the one-eyed killer; the physical difference that is present is supposed to represent the moral deviance of the character. Further, this author notes that some of the most popular and successful films in the past decade rely on these stereotypic representations (for example, *The Da Vinci Code, Lord of the Rings, Harry Potter,* and *Star Wars).* Currently, the villain in Disney`s recently released *The Lone Ranger* movie has a cleft lip and palate. More shockingly however, Scrivener (2013) brought attention to the publicity materials for the summer blockbuster which describe this character as "a ruthless outlaw whose terribly scarred face is a perfect reflection of the bottomless pit that passes for his soul" (News/Insight section, par. 12).

Additionally, throughout many forms of visual and print media, characters fulfilling the evil roles are often those who are "ugly" or facially different (Synnott, 2006). Longmore (1987) is one of the few authors to address how individuals with a *facial* difference are represented in the media. He points out that the physical differences most often seen in media tend to involve the face being affected in some way, which

dovetails with the criminal characterization portrayed. It happens very regularly that the level of evil in a character corresponds with the degree of facial difference. Hartnett provides the following example: "In *Goldeneye*, for instance, the moment that Bond's friend turns evil and betrays him coincides with the moment that he is physically disfigured, and thereafter the deformity represents all that is bad and lacks heroism" (p. 21).

Currently, television portrayals of physical "difference" are the most widely researched in American studies (Barnes & Mercer, 2003). This research reveals the common theme of using media representations to "other" those with physical differences, and emphasize that such people or characters are rarely seen in major television or movie roles. Unfortunately this is found in Britain as well -- in a study done examining British newspaper media, Barnes and Mercer (2003) found that representations of people with physical "differences" were highly stereotypical, and that these individuals were not depicted as ordinary members of society, but rather as people to evoke fear or pity.

As a practice of 'othering' and ostracizing people with physical difference these damaging stereotypical representations facilitate the marginalization of and discriminating against people with physical difference. When, through media representations, people come in contact with damaging stereotypes that are so pervasive and unquestioned, their opinions and beliefs of physical difference are formed and shaped (Dahl, 1993). And, while it is not always possible or easy to determine the precise effects of the media's attitudes and beliefs about others, it would seem that individuals with physical differences – including those with facial differences – are often influenced

negatively as well (Dahl, 1993), often leading to "socially disabling consequences"

(Turner & Stagg, 2006; p. 2).

There is a real concern that the media representations of people with physical

differences are often not accurate or representative of their actual experiences. Indeed,

those with the power to reinforce what we see as "normal" are able to ignore or

reinterpret (or misinterpret) the lived realities of those seen as second-class or non-

citizens (Schon & Rein, 1994). It is very dangerous to misrepresent lived experience, as

they are far too often "tenaciously framed by a few tired, restrictive, and largely

erroneous typologies" (Fudge Schormans, 2005; p. 80). Indeed, representations need to

more accurately reflect the lived realities of this group of people in order to provide

meaningful and useful information about facial differences, instead of relying on the

assumptions of people far removed from the real experiences

It is crucial to acknowledge that centuries of stigma, fear, and ostracism have led

to the current state where those with physical differences tend to be in a marginalized

position with little being done to rectify the representations of this group in the media.

Barnes and Mercer (2003) explore the more "positive" media images of physical

difference that have emerged in the last few decades. For example, since the 1980's,

characters with physical differences have appeared in a limited number of high-profile

advertisements for Kodak films, Levi jeans, and McDonalds. While some may argue that

this is a positive and even adequate change, the reality is that, in most cases, the disabled

character is created without consultation with people living with physical difference

(Jaeger & Bowman, 2005). Furthermore, we must recognize that the majority of

characters with a physical difference that are in movies or television are typically played

by non-disabled actors who can bring no lived experience to the role (Barnes & Mercer,

2003) and, therefore, we must ask ourselves what message that sends in and of itself.

Because the media has become such an important source of our knowledge about

human issues (Jaeger & Bowman, 2005) - in this case, physical difference – and because

it appears to often have an impact on how people with physical difference come to

understand themselves, it is necessary to challenge existing media representations of

physical difference (Auslander & Gold, 1999); to critically examine images of physical

difference and the frames and perspectives used when creating representations of this

population for the public to consume; and to work towards representations created by

people living with physical difference because these are far too often overlooked

(Charlton, 1998; Covey, 1998; Longmore,1987).

It must be acknowledged that it is not possible to understand what the exact

effects of the media on society's beliefs or opinions are (Dahl, 1993), nonetheless, this is

a necessary topic to explore as there is a lot of evidence suggesting the media creates

detrimental effects for those with physical differences by impacting how they view

themselves, and how others view them.

Facial Difference and Self-Esteem

As the purpose of this research was to hear from people who identify as having a

facial difference about how (if at all) the media has impacted them, I sought to find what

other research has been done looking at self-esteem amongst this population. The vast

majority of research in the area of facial differences is quantitative in nature. Utilizing

surveys, self-assessment tools, and questionnaires has been commonplace when assessing

individual's feelings of self-worth. Patrick et al. (2007) used tools such as the *Children's*

Depression Inventory and the *Quality of Life Outcome Model* in an effort to "produce

reliable, valid measures that can be used to consistently evaluate youth's self-perception"

(p. 539). Similarly, Starr (1980) used quantitative tools such as the self-administered *Self-*

Esteem Scale, and *Attitude Toward Clefting Scale* to discern feelings of themselves based

on their appearance.

In addition, Kapp-Simon et al. (1991) make use of the *Self-Perception Profile for*

Children and a true or false questionnaire called the *Personality Inventory for Children* to

attempt to measure their feelings of self-worth. The rationale for some authors to use

these tools includes the notion that "Instruments that capture the concerns of populations

with specific health problems are useful in comparing different patient groups with the

same diagnosis" (Patrick et al., 2007; p. 539). Further, Poorten and Louw (2002) believed

the use of such tools was adequate in catching mothers' reactions to the diagnosis of their

infants' cleft lip and/or palate (and this tool was administered both pre and post natal).

While it must be noted that quantitative research is a useful tool in some instances,

a recurring theme in the literature pertains to the need for long-term qualitative data.

Rumsey and Harcourt (2004) point out that there is a need for longitudinal research to be

done in order to explore how people adjust to their "difference" over a life span. Further,

Ryan et al. also note the need of qualitative research to be recognized and respected, as it

currently is jockeying for position in an evidence-based research world (2011). These

authors query why more qualitative research has not yet materialized; one reason for this may be that policy makers and organizations that work with this population are more familiar with evidence-based methods created typically by quantitative research.

As it stands, I feel comfortable with my choice to conduct qualitative research with this population, since there appears to be a gap in the literature as to what may be beneficial to this population. If it is true that quantitative data tools continue to be the prominent data collection method in research of self-esteem for those with facial differences, (Rumsey & Harcourt, 2011) then it can be argued that quantitative data collection cannot elucidate the same "depth of understanding from the perspective of the patients that qualitative data can" (Ryan et al., 2012; p. 734). This being so, I feel confident in my choice to conduct qualitative research as it has permitted me to hear from the participants in a more open and inviting way.

When Patrick et al. (2007) explain that "most craniofacial-specific outcome measures focus on provider-defined outcomes such as orthodontic, speech, and psychosocial outcomes" (p. 539), they reiterate how most research on the topic of facial difference comes from the position of the privileged medical and research team, as opposed to being directed by the participants. It can be understood that "Qualitative methods are useful for the study of human and social experiences, feelings, thoughts, motivations, expectations and attitudes – all of which are crucial to clinical knowledge" (Ryan et al., 2012; p. 734), therefore, tapping into first-hand recollections and accounts

through qualitative interviews and alternative methodologies is beneficial in extrapolating

a deeper understanding of the lived realities of this population.

Overall, the literature I examined appears to have a strong tendency to utilize

quantitative data and support a positivist framework. Through this analysis, it is evident

that there is a need for more qualitative data in the area of exploring self-perception for

someone with a facial difference. It is my hope that my research will aid in filling in the

aforementioned gaps in an effort to give a voice to the participants who may dislike being

limited to questionnaires like *The Facial Differences Module* - which on average took no

more than fifteen minutes to complete (Patrick et al., 2007) – and who may have more to

say than can be expressed through such quantitative tools.

Theoretical Framework and Methodology

Current Ways of "Seeing" 'Difference'

There are several different perspectives that create definitions and understandings of

disability, and I will explain two of them here. First, the medical perspective

"emphasizes that the disability is a biological or physiological function within the person.

The medical perspective classifies disability entirely within the person with a disability,

removed from any external factors. Under this socially conservative perspective, problems

due to disability are considered to reside in the individual independently of social context…"

(Jaeger & Bowman, 2005; p. 14).

This understanding is currently seen within the viewpoints of neo-liberalism - hence, the

emphasis for action is on the individual - on prevention, cure, and rehabilitation. If

however, we understand disability differently (as in much contemporary theoretical work

on disability) as "a socially created barrier, then…responsibility and accountability shifts

to the larger community" (Jaeger & Bowman, 2005; p. 12).

Second, the social perspective of disability operates first by separating the

construct of "impairment" from "disability" (although it recognizes the two are linked

(Hughes, 1999). Impairment is defined as "…continuously constituted and reconstituted

in terms of invalidation. To be impaired is to be perceived as invalid, to be seen to be

anomalous or contrary to order" (Hughes, 1999; p. 157). A social understanding of

"disability" asserts that disability is a result of human factors, "like a building being

poorly designed" (like inaccessible architecture, prejudicial attitudes, and oppressive

policies and practices) (Tregaskis, 2004; p. 11). "Impairment" is not the problem – what

matters, is how society responds to people with impairment. "Difference" is not the "fault" of the individual, but rather of society. Meaning, if society was organized in a way that it valued and appreciated "difference" and that took an individual with a disability's "needs into account" (Tregaskis, 2004; p. 11) then how we think of "difference" would be altered.

This way of understanding "difference" is indeed a sharp contrast to the hegemonic medical model approach. Through this frame, one can understand the "difference of impairment" as a natural phenomenon, one that is socially constructed (Hughes, 1999). As such, the emphasis for action is different – the focus is altering the social pathology that sees disability as a negative thing.

Rejecting the Medical Model

I need to be transparent and note that the perspective that I brought to my research, and to this thesis, is the social perspective of disability. As mentioned in the introduction, in this research I have chosen to use the term "facial difference" instead of the various clinical diagnoses that may have been given to individuals by doctors. In my own life, I have always described myself as having a "birth defect", but I am grateful that my MSW studies and this thesis topic in particular have led me to look more critically at how disability, including facial difference, is understood. As such, I am only now beginning to unpack and question how this negative label and the self-blaming that it brings has affected me throughout my life. This first-hand experience with a facial difference led me to approach my research from a critical stance rooted in the social perspective of disability. Neuman (1997) explains that critical research strives to go

beyond what society creates and understands as normal. Alongside Critical Disability Theory, this research will hopefully work towards social change for all people with disabilities.

It was my desire to conduct this research with the participants by using a critical framework which tackles some of the injustices experienced by disabled people with facial difference in particular; specifically, how facial difference typically is inaccurately and negatively represented in mainstream media. I called on Critical Disability Theory (CDT) to situate my understanding of facial difference and to guide my research. Informed by a social perspective of disability, CDT falls under the broader umbrella of critical theories and addresses the problematic way that disability and difference have historically been seen as a "deficit" within the individual, as opposed to a problem within the macro structures of society (Frazee, Gilmour, & Mykitiuk, 2006). The historical and dominant use of the medical model has led to facial differences being seen as a problem that requires "fixing" by medical experts, (in order to be "normal" or accepted) and even prevention in the future (Foster, McColl, & Fardella, 2007).

The medical model locates the problem within the individual, rather than seeing the "problem" as socially constructed (Darke, 2010). Meaning, the individual is to blame for their perceived negative attributes, and it is their responsibility to make the necessary changes to themselves in order to be accepted into society. It is from the CTD standpoint whereby I aim to aid in the attempts to de-bunk this long standing myth and suggest that the problems actually lie in the broader social attitudes and beliefs that create and maintain these stigmas.

Further, CDT views the language of difference as inherently related to macro political and social structures (Hosking, 2008). The findings from this research (which will be discussed subsequently) revealed that the words and images used to describe and portray facial difference in the media have indeed impacted the participants in terms of how they view themselves in comparison to "normal" people, and what value they ultimately see in themselves. In my experience, the language dominantly used to categorize facial difference includes terms like "birth defect", "deformity", and "disfigurement", but CDT rejects these labels and examines what language we use to understand and define difference, and further, to problematize what society sees as "normal" and desired (Hosking, 2008).

Aligning with the philosophy of School of Social Work at McMaster University, I agree that people are constrained by social and historical conditions and that there are often limited ways for certain groups to challenge harmful hegemonic 'norms'. Using CDT as a framework therefore shaped my research question, and led me to learn directly from a group of people with facial difference in an effort to learn their opinions on a social phenomenon that has historically cast facial difference as a negative thing (Snyder & Mitchell, 2010; Norden, 1994). In addition, I aimed to utilize a methodology that provided a space for people to share their thoughts and experiences in a way that moves beyond more traditional methods. It is important to note that my methodology/methods were informed by the work of my supervisor, Dr. Ann Fudge Schormans on media representations and people with intellectual disabilities (Fudge Schormans, 2010 a,b).

Turning to Qualitative Methods

As pointed out by Beresford and Evans (1999), methods that rely on quantitative data have historically been highly valued in our society, but these approaches acknowledge only limited definitions of "evidence". Further, the dominance of these positivist, quantitative studies has led to the individual questionnaire being one of the more widely used and valued methods for gathering data about social phenomenon (Madriz, 2000). Despite this popularity, I chose a different direction for this research; one which allows for the gathering of first-hand descriptive stories from research participants. As such, I chose to use a focus group as I felt it would allow for the production of qualitative data that provided insight into the attitudes, perceptions, and opinions of the participants (Kreuger, 1988). My decision to conduct a qualitative study serves an investigative purpose more than a concern to be statistically representative. This means that I gained depth in my interviews, rather than breadth. As Madriz (2000) points out, the focus group is a research method that is collective and strives for the multivocality of participants' beliefs, experiences, and perceptions, which is precisely what I was aiming for.

Qualitative research has traditionally relied on the spoken and written word (Horsfall & Titchen, 2009), which presupposes that people are able or willing to talk and write in order to contribute to the research. I had to account for the possibility that not all participants would be comfortable to discuss such an emotionally charged topic as media representation of facial difference. Because the research was focused on a critical exploration of visual representations of facial difference, the use of visual, arts-informed

research methods seemed an appropriate choice. Therefore, like Fudge Schormans

(2011), I used a combination of photo-elicitation and photo voice to let participants use

the medium of visual imagery to speak against visual representations of facial difference.

Visual research depends upon and redistributes social power (Denzin, 2000) as it allows

for one to re-create "our unexamined, taken-for-granted perceptions" (p. 727). It was my

aim to acknowledge that I was in a position of power within the focus group, but to also

invite the participants to share the power as much as possible by their use of visual

imagery and language. Doing so was a means for research participants to challenge

existing visual representation in mainstream media.

Photo Voice – Taking the Power Back

Photo voice was first developed by researchers Wang and Burris in the 1990's

(Rivard & Mitchell, 2013) while they were working with Chinese women in rural

communities. Used often as a part of applied visual anthropology, the object of photo

voice is to "enable marginalized populations to bring forward key concerns, to reflect on,

and to collectively engage in discussions on the issues" (2013, p. 137) and to do so by

taking photographs. In some ways, the photos do the 'talking'; they are used to show

people's feelings, concerns, and opinions on a particular issue. Regarding the participants

as the experts on the issue being explored, photo voice is action-oriented and researchers

often use the photographs and accompanying captions created by participants to serve as

evidence and thus promote critical dialogue to influence policy and decision-makers

(Rivard & Mitchell, 2013). As a result, I am able to see the consistency between this

methodology and my critical theoretical framework.

As will be made clear, the participants in my research were able to critique and discuss the issue of media representation of facial difference, and to then showcase their concerns about such by using their own visual imagery. While I am not so naive to think that this research will create *immediate* changes within the media, I do hope that it will be the beginning of a journey to provide more awareness for those who have never before questioned how people with facial differences are portrayed in the media at large. While it was not my original intent to address this research as action-oriented, I have noticed that several participants have discussed the topic of this thesis in the Facebook network group for individuals with facial differences. Indeed, the same individuals who came to the focus group stating they had never before thought about the issue, are now bringing it up on their own with other individuals.

Photo Elicitation – Images Lead to a Reaction

Photo elicitation is not new; it began in the 1950's with John Collier who used photo elicitation to attempt to get more conversation from his participants (Harper, 2002). Despite its presence for over half a century, photo elicitation is only more recently being used in ways other than for ethnographic interests (Harper, 2002; Clark-Ibanez, 2004) and in more critical ways (Fudge Schormans, 2011).

At its most basic level, photo elicitation means showing someone a photo and seeing what feelings, emotions, opinions, and thoughts are elicited by looking at the image (Harper, 2002). In research, images are inserted into interviews, allowing for an interaction between images and words (Katzew & Azzarito, 2013). Harper (2002)

explains that photo elicitation is used because of the way in which humans respond to the use of images and words in interviews versus just using words alone. In fact, "the parts of the brain that processes visual information are evolutionarily older than the parts that process verbal information" (2002; p. 13). As a result, images are able to connect with deeper areas of the human consciousness than words can. Harper (2002) also notes that more of the brain's capacity is used when it processes words and images at the same time.

There were a few reasons for incorporating these two methodologies into this research project. First, because studies have shown that interview subjects recall more details and converse more when photos are used as prompts (Wang & Burris, 1994), using images in the focus group allowed participants to examine, discuss, explore, and address something that was right in front of them, as opposed to something that may be more of an abstract memory. Secondly, using photo voice enabled participants to take the power back and to create images that they felt were more appropriate or accurate than perhaps what was being presented to them. In addition, these methodologies enabled me (the researcher) to access viewpoints of a group of people who have not always been given the chance to control how they are seen by others (Wang & Burris, 1997). Since the focus of my research was to hear first-hand from participants of or about their understandings of, and experiences of the effects of, media representation of facial difference, I believe photo voice and photo elicitation dovetailed well as methodologies for this research project.

Participant Recruitment – Finding the Voices

To recruit participants for this research, I put up posters around McMaster University campus (see Appendix A). In addition, I wrote a brief article about my research that was included in an e-newsletter for *Aboutface* International; a Toronto-based organization providing support to individuals and families with facial differences (see Appendix B). Lastly, I posted the same information about my research on the wall of a Facebook group called "Adults with Facial Differences Networking Community". The information provided in the aforementioned *Aboutface* and Facebook write-ups outlined the purpose of the research, what participants could expect if they took part, the potential benefits and risks, as well as the ability for them to withdraw at any time without losing out on compensation, and my contact information. (The posters gave more limited information but directed potential participants to contact me for more information if interested).

My insider experience as a person with a facial difference allowed me to connect with these two groups and explain why I felt this research was so important. It was necessary to provide context for the potential participants so they could make an objective choice about whether they wished to participate or not. My decision to recruit people age eighteen to thirty was related to my intent to address the issues associated with transitioning from youth to adulthood. My reasoning for this was that this time can arguably be challenging enough for anyone, without the added reality of a facial difference playing a role in creating and impacting the development of a sense of self.

However, given the page limitations of this thesis, the issue of transitioning could not be addressed.

As Kreuger (1988) notes, participants are selected because they have certain characteristics in common that are related to the topic at hand; the five participants in the focus group all identified as having a congenital facial difference. I will not elaborate further about the range of facial differences that participants identified as having for two reasons. First, it did not appear that the varying facial differences impacted how each participant interpreted or commented on the images. Second, and more importantly, because this is a small community, I must respect the participants' anonymity and not risk identifying them through further description here.

Resulting from the e-newsletter and Facebook post, I had initial interest from eight people. Several of these people connected with me through snowball sampling, which means that a few participants in the focus group recruited other people with facial differences (Kreuger, 1988). With regards to setting up the focus group, Kreuger (1988) points out that focus groups are difficult to assemble because they require many people with differing schedules and living in different places to be available at the same time. Indeed, three people who wished to participate were unable to attend due to the date and location. The focus group took place in a community room within a grocery store in Mississauga, which was relatively central for the participants, and provided neutrality and anonymity. While the recruiting material called for a two-day focus group, it actually took place over a four hour span in one day (due to participant availability).

Before the focus group began, I read over the 'Information and Consent' form,

and participants were reminded of their right to withdraw without being penalized. Each

participant signed the consent form and provided me with their contact information if

they wished to be provided with a summary report of the findings. Each participant

received a packet with copies of the twelve media images that were to be discussed that

day [1]. While I had produced a set of interview questions to guide me in the focus group, I

did not end up using them very much. Indeed, the conversation flowed from the

participants, which aligns with Kreuger's (1988) belief that focus group members

influence each other by responding to ideas throughout the conversation.

It must be noted however, that even though it was my goal to have the participants

lead the conversation and, in responding to one another, build on each other's opinions

and feelings, I (as the researcher) had much less control in this setting. This is not to be

confused with the thought that I wanted to have power over the process, but pertained to

how I could not ensure a question aimed at all participants was answered by everyone

before someone took the conversation in a different direction. I do not feel the research

suffered as a result however, because participants answered questions, the others were

able to develop ideas or connections from these responses and add their thoughts. Such

dialogue back and forth led to a deepening of the discussion, and further, to a richer, more

saturated creation of data.

Some researchers contend that focus groups participants should not know each

other (Harrell & Bradley, 2009; and Kreuger, 1988). This was challenging given that I

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[1] Please see the Appendices C-N for all twelve images that were presented to the group for analysis.

was calling on a relatively small community in the Greater Toronto Area - it would have

been very difficult to ensure that people were not acquaintances or friends. During the

focus group, P4 noted that he was relieved once he arrived and recognized people, as he

felt more comfortable sharing and speaking in this context. Nevertheless, as Harrell and

Bradley (2009) point out, when participants are familiar with each other there is a risk of

side conversations, and this was present in the focus group at times which was somewhat

distracting to me, and I presume to the other participants as well.

Ethics

        While this study received clearance from the McMaster Research Ethics Board,

there were some ethical tensions that had to be acknowledged throughout the process.

Namely, I was concerned with how I would manage the dual roles as both a researcher

(outsider) as well as someone with a visible facial difference (insider). Boushel (2000)

notes that, "Indeed in some circumstances, a shared…background may increase concerns,

for example worries about confidentiality within tightly-knit communities" (p. 82). I can

appreciate how this could have been a legitimate concern for some participants, as I

conducted recruitment through an agency which is known as a safe shared space for

people with facial difference. Lasala also remarks how "Researchers who interview

members of their own communities have noted that respondents sometimes fear

investigators will use their information to gossip" (2003: p. 20). This was important for

me to appreciate, in order to respect that sharing opinions in a focus group can be

challenging at times, without the added concern of the research participants worrying that

their contributions would not be kept confidential. To combat these concerns, I remained

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steadfast to my commitment to ensure all discussions that took place in the focus group remained confidential, and to keep participants' identities concealed.

Focus Group – How Did the Research Play Out?

As mentioned, the method I used to collect data is a focus group. Kreuger and Neuman (2006) describe a focus group as having between eight to twelve participants in a relatively unstructured interview. The focus group typically lasts a few hours, with the purpose being to discuss a concern, issue, product, or policy (Kreuger & Neuman, 2006). Given that I utilized both photo elicitation and photo voice as methodologies, I broke the focus group into two parts. To start, photo elicitation was used and participants looked at the twelve images that I picked for discussion. It must be noted that the images I chose may have been laden with personal biases, although I attempted to scan various forms of media for representations of facial difference that could be interpreted as either "good" or "bad".

Indeed, the images included various representations of facial difference from movies, television, print advertisements, and comic books. In addition, I asked participants to offer their thoughts about other images that they have come across, since it cannot be expected that I will have produced the most exhaustive and non-biased collection of images. Katzew and Azzarito (2013) suggest that one of the benefits of photo elicitation is that it encourages young people to explore hidden aspects of their lived experiences, in a way that touches deeper levels of their consciousness than words can do alone.

In the second half of the focus group, I brought in the photo voice aspect of the research. In truth, I did not use photo voice in its typical form (giving participants cameras to take pictures), but, like Fudge Schormans (2011), used Photovoice to support participants to create new images – a method still based on the principles of photo voice. Specifically, I invited the participants to re-create and re-design the images that we had discussed in the first half of the group. In this sense, I agreed with Wang and Burris (1997) that the images that were produced by the participants did further stimulate conversation, as well as direct people to feel a need for social change.

At the end of this process, I felt that the decisions participants made regarding the changes (or lack thereof) to the media images were not what I would have done. Denzin (2000) reminds us that it is important to understand how various constructions (both technical and social) influence how the photograph is made and interpreted. Indeed, how I viewed the images was influenced by my position as a Master's student coming at the research with influence from CDT. As such, while surprised by some of the decisions participants made, I suspect that when I was the same age as these participants I may have had similar responses to the images and, as such, no judgement is involved.

I believe that using a focus group as my tool to gather data was advantageous as participants were provoked into many powerful discussions as someone else provided new ideas to think about. In fact, Berg (2007) remarks that many more topics and ideas are likely to be generated in a group discussion than through conversations solely with an individuals. Moreover, the loose structure to this setting did allow for unanticipated topics to arise freely from the participants.

With this possible advantage of provoking thoughts in others comes a potential pitfall. It may be that participants were hesitant to say what they actually felt. Indeed, the topic of discussion calls on participants to share their experiences of having a facial difference; this may have been very emotional and difficult for some people. Furthermore, related to the reality that people in the group knew each other, some may not have been comfortable disagreeing with another participant's point of view.

Despite the known drawbacks, I felt that using a focus group for this research was well suited to my overall desire to demonstrate that an individual's knowledge is valid, and to give people a voice and a platform to share their experiences. The logic of my sampling strategy complimented the purpose of the study, which was to hear directly from people who have a facial difference about their thoughts pertaining to representation of this group in popular media.

Data Analysis

Given that I am conducting research from a critical lens, I am inherently addressing questions of power. In particular, I looked at the data to answer questions such as: Whose knowledge has been counted as legitimate in other research on the topic of facial difference and media representation? What effects (either positive, negative, or neither) have some of the images of facial difference in mainstream media had on the participants? How influential is the media in shaping or maintaining understandings of facial difference? What changes do participants want to see in the way facial difference is portrayed in the media?

After the focus group transcription was completed (by an outside transcribe), I studied the transcripts and conducted open coding to generate categories and themes present in the data (Strauss & Corbin, 1998). Specifically, looking at each sentence, I was able to identify the major ideas that were brought up by participants (Strauss & Corbin, 1998). In order to develop a deeper understanding of the data, I looked for explanations for participants' statements that included both macro and micro conditions that have shaped their opinions. In an effort to provide validity to the methodologies used, I asked the respondents to provide their feedback on the images (Strauss & Corbin, 1998) that were altered to their specifications (work that was done after the focus group took place). The participants who responded stated that they felt the images did indeed represent what the group had intended.

Throughout the entire data analysis process, I had to reflect on how my experiences with a facial difference have biased me in the way I saw the images, and the decision I made to approach this research critically. Above all, I believe I set up the process of data analysis in a way that was consistent with the method I had selected since I was asking participants to reveal information that involved looking at media representations critically.

Findings and Discussion

The focus group revealed many important issues pertaining to the topic of facial difference, including society's notion of beauty; how individuals with a facial difference understand themselves in Western culture; and to what extent the media is responsible in shaping and promoting our understanding of "normal". The majority of the identified issues cannot be addressed here given the restraints of this thesis. I have chosen here to focus on the important revelations made by participants' critiquing the media representations presented to them. Stemming from the above-noted three themes are the issues of "othering", language, eugenics, and the termination of life, and society's notion of beauty. I address as well the ways participants justified their decision *not* to change particular images. These fall into three distinct categories: 1) Participants did not make changes to the image; 2) Participants made minor changes to the images; 3) Participants made major changes to the images.

As mentioned in the Methodology section, I found it very interesting that after the focus group was completed, I discovered that many of *my* initial impressions and thoughts about these images did not align with those of the participants. I found this reality to be difficult to negotiate, as I wanted to ensure I was not leading the critical conversation about how *I* perceived this phenomenon. However, given the similarities in experiences between me and many of the participants, I did have to work hard to manage my emotions and biases so as to not influence the focus group, as well as the analysis

afterward. As a result, I decided to critique the images as well and to incorporate this

critique into my analysis and the writing of this chapter in order to allow for my insider

experience to be acknowledged, but without pushing this onto the participants.

In order to provide the reader with a rich understanding of what the participants'

shared, participants' quotations will be used alongside pertinent literature and my own

critical reflection on the ideas emerging from the participants' work with these images.

No Changes - *"This image is pretty happy…"*

A total of five images were left unaltered by the participants: Shrek (Appendix C),

Disney's Hunchback (Appendix D-1); Two Face (Appendix E-1); Boardwalk Empire

(Appendix F); and Roxanne (Appendix G-1). I decided to change three of these five

images when it was my turn to engage in the critique, leaving only Shrek and Boardwalk

Empire entirely unaltered. Unfortunately, the restraints imposed by a Master's thesis

preclude a comprehensive discussion of all altered images. Therefore, I have decided to

focus on one subject from this category; an image that the focus group left unchanged but

that I made alterations to. The image that will be discussed first is one that the group

determined did not need to be changed and is the comic book character, Two Face.

Adams, N. *Batman Annual* Vol. 1 (14) (1990)

"Two Face" is a character from the series *Batman* and first appeared in a comic book in 1937 (The Comic Book Database; 2013), but the image used in the focus group is from 1990. I explained to the participants that this character is typically portrayed as a "good guy" named Harvey Dent who is involved in politics, as the District Attorney of Gotham City, who becomes the villain named "Two Face" after an accident where one half of his face is burned by acid or fire (this varies depending on different versions of the comic book or movie portrayals).

Over the years, Two Face has been a re-appearing character in this series, and has been visible in comic books, on several animated television shows, and in multiple

movies (played at different times by famous actors such as Tommy Lee Jones and Aaron

Eckhart). At different times in the focus group discussion, the participants appeared

unsure about this character. Keep in mind that participants had, in the early part of the

focus group, been shown all twelve images and given a brief summary of each. Looking

again at this image of Two Face, one participant pointed out that a few images presented

were of characters and people with scars. This participant stated they were:

> "…portrayed as evil because they have a scar on their face and because they look
>
> different that means they are scary. That is what I think the media has done to
>
> us" (P1).

Another participant remarked that oftentimes, when one sees a scar on a stranger's

face, "you automatically think they are bad…" (P3). The group discussed how these

stereotypes lead much of society to "jump to believe" that a facial difference translates to

villainy. As the discussion continued, P4 remarked that he sees an increase in movies

where "scars and marks on their faces tend to mean [the character] is a bad guy". It was a

unanimous belief in the focus group that in their experiences, characters seen in the media

with facial differences are castigated and are far too often seen as arcane or undesirable.

With regards to the Two Face image, another participant noted the troubling

correlation between being subject to an acquired facial difference and morphing from an

attractive, successful community hero to an unsavoury villain:

> "the part that bothers me about *Batman*…the fact that [Harvey Dent] was a
>
> good guy and then it was only because of his face that he became a bad guy"
>
> (P3).

This observation is one that I anticipated, as the most recent *Batman* movie portraying

Two Face (*The Dark Knight,* 2008) emphasizes the transformation exactly how this

participant described it.

Longmore (1987) remarks how imposing a facial difference onto a character like

Harvey Dent reinforces prejudices against this population: that the facial difference is a

punishment; that the character is now bitter due to this 'fate' and that this character

resents those without facial differences and would seek revenge (when possible). As it is,

Two Face falls into all three of these stereotypical pitfalls, and it reinforces the subtext

that a facial difference is something to fear and to be ashamed of. Further, this author

argues that when physical differences are seen in media, visible "disfigurement of the

face and head" (p. 68) is utilized to represent a negative reflection of the character's

personality or soul.

My concern, as mentioned previously by P3, with a character being dubbed the

'white knight' at the beginning of the movie but then the 'villain' after half of his face is

burned is the message that is thus being sent to the viewer: characters are inherently bad

or evil if they have a facial difference. This is particularly concerning given that this

movie alone grossed over five hundred million dollars in ticket sales domestically

(Hughes; 2012), which means this powerful message has been given to a large number of

people. It is often such representations of difference in the media that lead to negative

personal responses to disability or difference (Gartner & Joe; 1987). P3 echoes this

concern when she stated "…if I was to watch [The Dark Knight] and all I saw was that

[Harvey Dent] had the burn and then all of the sudden he is bad…that could be taken really [negatively by the viewer]."

If we can assume that many people have no first hand experiences with a facial difference, and if perhaps these same people do not regularly interact with individuals with a physical difference, then one must wonder where society develops attitudes and understandings of facial difference. Enns and Smit (2001) suggest that various social institutions such as government, school, and family all participate in shaping attitudes about "difference"; however, they believe that the dominant ideas present in our everyday understandings are derived in large part from movies and other popular media forms that we surround us. Further, Kitzinger (1998) and Enns and Smit (2001) explain that media plays an important role in shaping what the audience sees and hears. Such experiences play a large part in shaping what one thinks about their world, particularly when one has no pre-existing experience or knowledge. In addition, McCombs, Danielian and Wanta (1995) argue that the media indeed plays an instrumental role in providing society with information.

Othering

Fook (2012) defines 'othering' as "a process in which social difference is constructed. Binary categories are created and differences are constructed in binary oppositional ways" (p. 196) - typically 'us' versus 'the Other'. Further, in his exploration of disability representation in public photography, Hevey (2013) discovered that individuals with physical differences are present in images almost exclusively to act as

symbols of 'otherness'. Similarly, Barthes (1957) notes that those in mainstream society tend to be uneasy with people who are different from them; as a result, these 'others' are often neutralized by the majority by way of curing or eliminating them.

The notion of 'othering' people with a facial difference was brought up by P1 during the conversation about the Cleft Lip Ad (See Appendix N). As she discussed this representation, she noted that it made her feel like "the ad is pitying *us*" (italics added) and identified with this total stranger as an equal, because of the commonality of a facial difference. Later on in the focus group, P1 aligned herself with Two Face and defended both herself and this character by stating: "I am – we are not bad people". The context surrounding this comment was that Two Face became the "bad guy" once he had a facial difference, and P1 was explaining that she, and anyone else with a facial difference should not be thought of as "bad" simply because of how their face looks.

At another point in the focus group discussion, P4 explained that he often sees characters in the media being made to feel less than, or 'othered' based on their looks. When referring to someone he saw on television who was 'othered' because she had acne, he said: "Her being herself was not acceptable…[it] made me feel like I was not acceptable because I did not match [society's beauty ideals]". Many participants felt that their reality of looking "different" than what society tells us is beautiful or "normal" leads them to feel like they are "othered", inept, and less than. P1 explained how, in relation to the Cleft Lip Ad, this act of 'othering' makes her feel: "…it kind of makes other people think we are something else…like we are incapable of doing things."

The discussion on Two Face ended with P5 again explaining that it was not "just because he was deformed" that Harvey Dent became "evil": there was a lot more to the story. Such justifications were surprising to me as they highlight the power that pervasive media representations have, in that someone with a facial difference is able to defer from the critique of an inaccurate and oppressive representation in favour of an explanation which excuses these "pathologizing practices" (Chivers & Markotic, 2010; p. 9) which dovetail the notion of a facial difference and 'badness' together.

Participants' justification for not altering the image

The opinions of Two Face swayed between participants. On the one hand, a few individuals thought that the correlation between the accident and the turn to villainy was sending a negative message to the viewer, but P5 was intransigent and felt strongly that the character turned "bad" because of his history with the justice system. Stemming from P5's aforementioned explanation as to why Harvey Dent became a villain, some of the participants' views of this representation of facial difference changed. He explained:

> "…there is a lot more back story in comics than movies, and I think he
>
> [Harvey Dent/Two Face] feels that the justice system let him down and never came
>
> to back him up and now he is going to get back at them." (P5)

With this explanation, P5 suggests that his facial difference is irrelevant to the plot line, which contrasts with many researchers who see physical difference used in media for dramatic effect. While P5 sees Harvey Dent's turn from "good" to "bad" as indicative of his exhaustive struggle with the justice system, Hartnett (2001) argues that characters

with "differences" are not utilized for their uniqueness and complexities, but rather for their identifiable "impairment" which is often exploited for dramatic effect. Furthermore, Barnes and Mercer's (2003) research of British television programs found that characters with "differences" are not seen as ordinary members of society but as stereotypes used to evoke specific emotions (such as pity or fear). Indeed, Two Face becomes someone that the people of Gotham City pity, and that other villains fear.

What also needs to be addressed is the fact that many people watch this movie without the detailed knowledge about the backstory that P5 had, and are left to understand what it means to have a facial difference solely based on this demonstrated transformation from hero to villain. Indeed, P3 mentioned she was not familiar with this series or the character, and noted her concern that there was such an immediate (and negative) transformation. The other participants did not raise any concerns about how viewers might interpret this representation without the background knowledge that P5 uses to justify the dramatic change in Harvey Dent.

At a later point in the focus group discussion, I asked if participants were okay with how the storyline played out for Harvey Dent. At this time, P1 supported P5's justification and offered her own: "…I think anything could cause anybody to go crazy if they don't have the strength or the willpower to keep a handle on themselves." P1 appeared to be suggesting that other factors must be accounted for when examining this character and his immediate change from 'good' to 'bad'. Moments later however, she noted that she is uncomfortable with the correlation that once someone has a facial difference, they are necessarily bad. Again we see that some of the participants struggled

with their position of this representation, as P1 changed her mind several times about whether this character's turn to villainy is justified, or if the change from "good" to "bad" is perpetuating a negative stereotype about facial difference.

It is also important to pick up on her insinuation that a facial difference would justify someone turning "crazy". The literature also points out that the media far too often creates characters with differences that then have an increase in self-loathing and loss of control (Longmore, 1997; Bogdan,& Knoll, 2012). When the media suggests that a facial difference is somehow a loss of "humanity" (Longmore, 1997; p. 68) and therefore the person is seen as unstable or dangerous, it continues to feed the viewer's understanding of "difference" as something to fear or avoid. Bogdan and Knoll (2012) point to the example of "Dr. Strangelove", who is a character from the 1964 film *Dr. Strangelove or: How I Learned to Stop Worrying and Love the Bomb*. This character is a former Nazi who serves as a nuclear war expert to the President of the United States, and has diagnostic apraxia or "alien hand syndrome" (IMBD, 2013). Here, the viewer sees a link between "difference" and irrational or "crazy" acts of destruction. For example, this character is labelled as having a "difference" that is suggestive of something to be scared of, as he is the film's antagonist who is in a wheelchair.

My Changes - Where I felt more needed to be done to de-construct in order to re-construct these images.

During the discussion on Two Face, I found it both startling and disconcerting that the participants did not take greater issue with the stark transition from "good" to "bad" that occurred at the exact moment the character Harvey Dent acquired a facial difference.

I can see in the transcripts that I pointed this out as problematic, and as previously noted, P3 and P1 did wonder if this was wrong. However, given that none of the participants felt it was necessary to change the image or context of Two Face, I was left feeling that this issue still needed to be taken up. Indeed, I struggled a lot with this, as the message of this characters turn to evil hinges on him acquiring a facial difference. As someone with a facial difference, I cannot help but feel that I too must be "bad" or "wrong" since I do not look like society's idea of "normal". I felt it was necessary to take up this image in order to demonstrate that just because someone has a congenital or acquired facial difference does not make them a bad person, or someone to fear.

Bogdan et al. (2012) explain how the idea of a monster is linked with something frightening and scary. This understanding seeps into movies regularly, and the dangerous and monstrous characters tend to be the ones committing disturbing acts. But they are typically the ones who are "deformed, maimed…and have…other physical…disabilities". Therefore, the connection the audience might make after watching a movie such as *The Dark Knight* is that facial difference goes hand in hand with evil, terror, and fear.

As such, my main concern with how this character is represented in the media is that someone with a facial difference can *only* be evil. I could not agree with the participants who felt it was a satisfactory representation of a facial difference. My changes involve positioning Two Face as a "good guy" – still in politics and on the same quest for justice in Gotham City. To accomplish this, I used an image of Two Face taken from promotional materials for the movie *The Dark Knight* in order to overemphasize the contrast of both sides of this characters face: one side of the face with the blonde,

attractive actor, Aaron Eckhart. This is juxtaposed with the side of his face that has been made up to apparently expose muscle and burns resulting from the accident. I then found an image of an American political poster online, and created a fictional campaign poster for Harvey Dent / Two Face. The purpose was to create a poster that Harvey Dent/ Two Face might use when running for District Attorney, which would suggest that the character did not become a villain after his acquired facial difference, but rather was able to continue to contribute in a meaningful way to his community.

The image of the actor Aaron Eckhart was not viewed or discussed in the focus group; however, the participants were informed that they had free range to re-create the images in any way they chose. I allowed myself the same ability to re-create the image however I deemed necessary, and the image below is what I created utilizing the same editing program (Photoshop and an assistant) which participants had access to as well.

I felt these changes were needed in order to highlight that someone with a facial difference can be (and is) a "good" person. Additionally, in the context of this character, it suggests that Harvey Dent/ Two Face can still be a positive member of society and run for election, and be the 'white knight' despite having been in an accident and left with a facial difference.

Stephanie's Changed Two Face

Minor Changes

The focus group participants made minor changes to five of the twelve images: Mask (Appendix H-2); CNN Banner (Appendix I-2); Birth Defects Ad (Appendix J-2); Man Without a Face (Appendix K-2); and Harry Potter-Villain (appendix L-2). By minor changes, I am referring to the participants' decision that the original image remained mostly intact – the alterations were not extensive. Of these five images, I agreed with two of the participants' adjustments, (CNN Banner, and Harry Potter-Villain) but changed three of the images (Mask, Birth Defects Ad, and Man Without a Face) in different ways (and to a greater extent) than did the focus group.

The image that will be discussed here is the still photo from a CNN story about a surrogate mother, Crystal Kelley, who decided against an abortion after an ultrasound

given at five and a half months into her pregnancy revealed the baby had some medical complications, including cleft lip and palate (Cohen, 2013). The headline for this photo says: "Surrogate defies wishes of family; refused to terminate pregnancy despite birth defects". I chose to discuss this image and its alterations in this thesis because its presence in the focus group led to evocative responses from the participants. Additionally, my personal bias may have played a part in choosing this image to highlight as a discussion piece, since I relate to some of the struggles this child will face in her life.

According to the CNN story, Kelley refused the offer of $10,000 from the biological parents to abort the child. I explained this story in brief to the focus group, and showed them the image (see below); their reactions to this photographic image led to an emotional conversation about language, eugenics, and termination of life.

Cohen, E. March 16, 2013.

Language – Do the Words We Use Matter?

A key theme emerging throughout the focus group was the use of language in our media. We know that language is used in all cultures to shape ideas, perceptions, and attitudes (Government of Canada, 2003). Haller, Dorries and Rahn (2006) argue that the language used in our society strongly impacts how we see and understand marginalized groups. Moreover, Jaeger and Bowman (2004) point out that to come to an understanding of 'difference', one needs to account for the social factors at play: namely, the assumptions, and representations and classifications of "difference" that we see and hear in everyday life.

Words have often been used (intentionally or unintentionally) to denigrate the "Other", those who are seen as "different" from mainstream society. Haller, Dorries, and Rahn (2006) argue that it is crucial to examine the terminology used when referring to difference, as it assists us in seeing if the media is becoming more "disability aware" (p. 62) in Western society. While some people may think that words do not matter and are far too mundane to deconstruct, I agree with these authors that language does in fact have an influence over how society at large views difference, and even more, how individuals with a facial difference come to understand themselves. Given that words can be understood as a reflection of a particular society's beliefs, it can be argued that individuals with facial differences are constantly engaged in a battle to achieve acceptance and integration in a society that very often relies on historical understandings of difference that are both stigmatizing and ostracizing.

In the discussion about Kelley and her daughter, participants felt it was important to label and explain what these "birth defects" are so as to provide people seeing this image with an education and an accurate understanding of the situation: "…and even saying 'cleft' instead of 'birth defect'" (P3). At other times throughout the focus group, this theme would again come up: at one point P3 explained that identifying the condition of cleft lip and palate would provide "…a little bit of awareness or something. [Cleft lip and palate] is one of the most common yet nobody knows about it". Furthermore, when discussing the image that was an advertisement asking for donations for surgeries on cleft lip and palate (See Appendix N), P5 explained that "…defining a term like cleft lip and palate [is necessary] so people can be educated on what she has, rather than just what the picture is of".

P5's comment picks up on the importance of deconstructing language, and valuing what a person is beyond the label assigned to them by dominant groups. Haller, Dorries, and Rahn explain that "the…majority…generally resist language shifts, often derogatorily labeling them as 'just political correctness'" (2006, p. 62) which explains why there tends to be resistance to new (and more appropriate) understandings of "difference". Further, they remark that mainstream media tends to be very slow at accepting and utilizing new terminology (terminology which might be more acceptable to the marginalized group). This is problematic as it shows us that it does take a conscious effort to break down myths and stigma associated with facial difference. P2 also explained how she felt after viewing the Cleft Lip Ad, and the lack of education around this facial difference:

"It just kind of brings my self-esteem down. It is like if people say that you

> look like 'this' [pointing to girl in ad with cleft lip]…it is like they are
>
> indicating that you don't look like a normal person, or you don't look
>
> beautiful"

The participants felt this could be avoided if the ad contained the actual name of the "difference", as well as some information about the struggles people face when they have cleft lip and palate.

Participants were told they were able to change the images however they chose – including altering the text as part of the photo voice aspect of the research. I felt that providing a space for participants to choose alternative words and phrases to accompany the image and thereby impact its meaning was an empowering exercise, as it allowed them to re-shape how people might see the image, read the story, and come to understand this baby and Crystal Kelley. Phillips (2001) reminds of that language and an image dovetail together as:

> "An image communicates by means of its association with some hidden
>
> or implicit text that carries that image into the domain of readability; prevailing
>
> ideology, social stigma, and memory contribute to the dialectic between the
>
> image and the text" (p. 208).

This echoes Parashar and Devanathan's (2006) argument that language plays a large role in perpetuating false or unfounded representations of physical "difference". The group members all agreed that they wanted it to be a positive message, and they saw the baby as looking rather happy in the image.

P3- "I know in one headline you can't necessarily tell the whole story, but

like even 'surrogate accepts child with cleft' instead of saying that [she]

did not terminate, you want to tell the story -- that the parents wanted to terminate

and she did not --even just saying like "accepted the child"…"

The following is what they decided to change the headline to: "Beautiful baby born into

loving family"

"Focus Group's Redone CNN Banner"

Termination of Life – Where Do We Draw the Line?

Another impactful discussion that arose from the participants' working with this

image was that of termination of life – specifically in the case of a fetus with a facial

difference. The immediate reaction to the image from two participants was their horror

stemming from their interpretation that people involved with this baby were discussing

ending its life. P1 felt this discussion equates to an understanding "…they are not going to

be perfect? [Then] I should just kill them". Similarly, P5 understood this to mean that

"they jump immediately to that like let's kill her because she is not going to be perfect".

Participants each had personal accounts of their own experiences with this notion of terminating the life of a disabled or different fetus. P1 shared:

"-- I have eleven fingers—and [cleft lip and palate]-- I am glad my Mom

did not terminate me but, why is that legal to kill somebody else before they

are born because they have a facial difference? Like other than the way they

look they are still like a good part of society."

Related to the discussion of language, P1 explains how the wording of the CNN banner could have told the same story, but in a different light. She felt that the way the story was presented, it was suggesting "…like look at this poor child, we should've killed it…" but had the wording been different then the story could have a different (more positive) meaning. When discussing Kelley's situation, P5 remarked, "That is a live person…that they are talking about…like we should kill her?". It was clear from the comments from the participants that they felt shaken by the reality that the discussion of abortion does arise as related to in-utero diagnosis of "birth defects".

Further, P1 felt the message was clear that "The point in [this] thinking is '[the baby] won't be perfect? I should kill them'" Added to this is the notion of society ideals, and what is often thought of as "perfect", P1 expressed her concern that "…they all jump immediately to 'Let's kill her' because she is not going to be perfect". Davis (2013) provides context to this contested notion of perfection and explores how many people have a tendency to compare themselves to others. In reality, the term "normal" only came into the English language in the mid nineteenth century (Davis, 2013). In Ancient Rome,

ideal Gods and Goddesses were created by extrapolating features from many different images. As such, there was no possibility that any *one* person could be "perfect", and there was not the same social pressure that we see today to meet these beauty ideals. In recent time, however, the concept of "normality" is seen as related to evolution, and the Western notion of progress (Baynton, 2013). The notion of eugenics and evolution will be discussed shortly.

Is 'Difference' Really that Uncommon?

Jaeger and Bowman (2005) point out that statistically speaking, if you live long enough, you will develop some kind of disability or 'difference'. In fact, they explain that only fifteen percent of people with a disability were born with that condition (p. ix). While the focus of this thesis is on facial difference and not disability broadly, it is important to acknowledge that disability and 'difference' can happen to anyone at any time – through an accident or medical condition. This reality is not meant to create anxiety in the reader, but rather to illustrate that 'difference' really is not that uncommon – some would argue it is in fact ordinary – and therefore should not be treated as something to reject or fear.

One's choice to have an abortion is obviously a sensitive issue, and many factors must be appreciated (including but not limited to, culture, religion, personal experience with a facial difference, and even finances in some cases). However, Strauss (2002) notes that we do not know much about how families and medical professionals come to a decision about abortion or not after a diagnosis has been made in-utero. Both Jones

(2001) and Saait (2001) urge practitioners to be aware of the manner in which information about a facial difference is relayed to the parents, as it is becoming more common "that all biomedical efforts must be exerted to reduce and repair disfigurations and disabilities in newborns" (Strauss, 2002; p. 164). Indeed, when parents are faced with the news that their child is "different", it can be assumed that a wide variety of emotions will be experienced. When turning to medical professionals for support or assistance, we must be aware of how information is being relayed about the child's facial difference, as the "weight of authority of the physician might in and of itself constitute coercion" (Matthew, 2001; p. 182) to opt for abortion over birth.

A study by Blumenfeld et al. (1999) revealed that when diagnostic testing revealed cleft lip at thirteen to sixteen weeks in a pregnancy, 23 out of 24 parents chose to abort the pregnancy. Cultural and societal factors must be accounted for as this study took place in Israel, but nevertheless, one must question whether the decisions made by parents are reflective of messages received from the mainstream media. In fact, Strauss (2002) argues that:

> "conformity is also seen in advertising and media images and in the societal
>
> pressures placed on persons with [differences] to normalize by surgical and
>
> other treatment efforts" (p. 165).

In an article by Evans et al. (1994), the researchers (where sixteen of the seventeen authors are doctors) explain that "development of selective termination has allowed couples in this very unenviable situation" (p. 94) to endorse selective termination under

circumstances where there is a child with a disability or difference. Describing a child with a facial difference or other "condition" as *unenviable* is in itself cause for alarm, if this is in fact how many doctors view such a situation. It begs the question of who in fact should play a role in deciding what is "desirable" or "normal"? And moreover, should doctors be more cognisant of how their opinions might inappropriately sway a parent's choice, when the doctor may not actually "know" what this child's future holds (Strauss, 2001)?

At this time, P2 spoke up and shared with the group her recent experience discussing termination:

> "I actually had this discussion with my genetics counselor on Tuesday and he told
>
> me that [I] have the option of seeing if [I] have a baby who has a facial difference…
>
> and you get to decide if you want to keep having that child or [have an abortion] and
>
> I am like 'Okay, but why on earth would I want to not have a baby even if the kid had
>
> a facial difference…?' And he said 'I don't know -- would you want the baby to live
>
> the life that you lived?'… What goes through doctors' heads?"

Hubbard (2013) brings this topic to light when discussing the heavy burden such discussions place on expectant parents. Specifically, he explains that if an expectant parent – in this case, P2 – were to 'choose' to have a child despite the 'risks' of that child having the hereditary condition that she has, then her family, and the rest of the world could potentially reproach her for having 'caused' the baby's physical and social pain, when she could have prevented it. As a result of this unfair burden and difficult decision, many women 'choose' to abort pregnancies when they are made aware of "birth defect'".

One way that this is particularly alarming is that (as previously mentioned) we tend to forget that any one of us could acquire a physical or facial difference on any given day – as a result of an accident at work, on the street, or as a side effect of a medical condition (such as Bell's Palsy for example). CDT would question whether a doctor's efforts to 'save' a child and family from future pain and suffering as a result of a facial difference is really about avoiding these assumed hardships, or perhaps it is done because having a facial difference is often seen as a social and economic burden. Similarly, Strauss (2002) questions whether society plays a large role in creating and maintaining our tolerance (or lack thereof) for "difference".

I found the participants' personal accounts of their life with a facial difference to be heartbreaking for several reasons. To begin, this CNN story is obviously hitting close to home for the members of this group - each person has a facial difference and seemed to feel the personal attack being made against Kelley's baby as an attack on each of them as well. Secondly, the very fact that P1 felt that, in some way, the appearance of someone with a facial difference has a negative impact on society yet *other* than that aspect, these people are still "good" people, is very disheartening.

Specifically, this sentiment reflects the reality that many people with a facial difference experience a concomitant circumstance, whereby their lived reality of looking "different" leads some to have to defend themselves to the world and prove that they are not a "bad" person. Susman's (1994) research into stigma associated with disability illustrates that the self-valuation of someone with a physical difference often hinges upon the representative images we see in our culture of "difference", the stigma associated with

it, and how the "normal" majority respond to and treat these individuals with physical "difference". Assuredly, this CNN banner does not provide me with a positive feeling of myself, as I very much relate to the child who is being chastised for existing by many "normal" people.

Eugenics

Strongly correlated with questions of termination of pregnancy in the case of a fetus with a disability and facial difference is the science and practice of eugenics. The reader may be familiar with the topic of eugenics. For those who are less familiar, eugenics was at its height of popularity in the early twentieth century and can be understood as the science of biologically improving the human race (Alemdaroglu, 2006). The term *eugenics* means 'well born' and is derived from ancient Greek, but was coined in 1883 by Charles Darwin's cousin, Francis Dalton (Hubbard, 2013). Bogdan (2012) explains that "during the eugenics era, it was widely believed that a person's physical features, the shape of his or her body, and facial appearance revealed basic information about his or her moral character and mental abilities" (p. 76).

The reality of this practice is that it targeted minority groups (such as the poor, women, people with disabilities, and people deemed to be criminals) and looked at hereditary factors as an explanation for the perceived "problems" (Allen, 1986). Eugenics was a social movement that was predominantly seen in Western Europe in the early twentieth century, but was also favoured in North America (Allen, 1986). Many advocacy groups at this time called on social workers to assist in bettering these "social problem

groups" (Welshman, 1999; p. 460), and the practice of eugenics was relied upon to "eradicate what was seen as unsavoury" (Welshman, 1999; p. 472), which would have included individuals in poverty, or those with physical or mental "defects". Further, "Eugenicists' believed that inferior persons would affect later generations by passing undesirable traits to them. As they saw this situation, this detrimental cycle needed to be stopped" (Bogdan, 2012; p. 89).

Mackelprang and Salsgiver (1996) bring attention to the fact that the social work profession did play a part in the eugenics movement. Specifically, they explain how the profession has been hesitant in the past to be committed to or allied with individuals with disabilities or "differences". As noted in the Methodology section, the medical model (which includes social workers as health professionals) sees individuals with differences as passive recipients to their expert opinions and beliefs. Social workers did in fact play a part in removing decision-making and control from individuals seen as "different", (Mackelprang & Salsgiver, 1996) thus contributing to the on-going battle for this group to maintain control over their lives. Of course, it can be appreciated that social workers have a positive history of supporting and advocating for oppressed groups, but the profession, in this case, has often been supportive of eugenics and related practices. This is problematic as those targeting by eugenicists and their allies are devalued, and often not regarded as worthy of living.

Returning to P2's discussion with her genetics counsellor, another reason why making such 'life' or 'death' decisions in the case of a fetus with a disability or facial differences is problematic is related to the practice of 'new eugenics'. Currently, many

disability activists regard selective abortion as 'the new eugenics' as it is done with the intent of eliminating or avoiding certain categories of people (Saxton, 2013). It must be noted that I am not suggesting that a woman does not have the right to decide whether to terminate a pregnancy; I believe she does. However, when medical professionals (and social workers) promote prenatal testing and diagnoses for the purpose of consideration of abortion, it ought to raise an alarm. Such a thought causes personal distress, as I am forced to think of whether my mother would have felt the pressure to 'choose' not to have a child with cleft lip and palate had she been given this option 28 years ago.

Garland-Thompson (2013) points out that there has been an intensified shift toward a desire to fix, control, or eradicate that which is not seen as "normal". This can be attributed in part to the hegemonic medical model that is still pervasive in our society and its commitment to healing and curing that which is seen as sick or broken. This, coupled with modern technological advances which we often call on to intervene in our 'problems' has indeed led to a reality that people are left with the choice to decide who does or does not get to inhabit the world.

During the discussion of the CNN story, P4 asked an important question after P2 shared her experience with the genetics counsellor:

"I want to know if doctors say that to everyone – so [for example]…in a small

town where most of the population is white and there is a black couple trying to have

a baby, are [doctors] going to say to that couple' well because of the town you are in,

do you want to have a child?' ---- like I want to know if doctors say this to all parents;

> if they are not going to come out like perfect babies at that point do you still say
>
> things like "are you sure you want to have this baby?' -- if you are say it to one group
>
> of people then you say to all [people]."

Hubbard (2013) validates this question and explores the practice of pre-natal testing. In particular, he suggests that the majority of people would be horrified if testing was done on mixed-race couples to determine if they were to have light skinned children. He proposes that it could be argued that since there has been evidence to suggest it is difficult to grow up Black in America then people could be spared the suffering by avoiding the births of dark skinned children. However, what I and many others would counter is that such practices would be irresponsible, racist, and serve to negatively impact those who do exist and have dark skin, as racial prejudices would be reinforced.

While this example is hard to imagine, it serves as beneficial to the topic being addressed here. Hubbard (2013) asks how is it possible that many view such pre-natal tests pertaining to the prevention of 'birth defects' as progress? To be sure, nearly a century after the atrocities that occurred around the world during World War II rooted in eugenics, we are yet again turning to a small group of scientists and physicians to engage in the discussion about who should or should not be born.

Major Changes – *"I can tell he is a bad guy"*

The participants made major changes to two of the twelve images: James Bond Villain (See Appendix M) and the Cleft Lip Ad (See Appendix N). By 'major changes', I mean that the participants altered the image so that the message being given was vastly

different than how the participants originally interpreted it during the photo elicitation discussion. This section will focus on the participants' work with the image of a villain from the *James Bond* movie franchise. The character's name is Blofeld and he is depicted as an evil genius who is Bond's biggest nemesis (IMBD, 2013). I have chosen to discuss this image at length over the other, because I think it is necessary to redress the idea that a facial difference needs to be removed in order for someone to be seen as "normal".

The image below was shown to the participants, and when describing this character, I pointed out that in my opinion, (and re-affirmed by Hartnett, 2000), the majority of *Bond* films have a villain with a facial difference, and that this character is no exception. It is often the case that the level of evil in a character corresponds with a physical deformity or difference (Franks, 2001; Hartnett, 2000). Blofeld is in several books, video games, and movies pertaining to the *Bond* franchise (IMBD, 2013). In two of the six films in which this character appears, viewers only see him from the waist down. However, in the last four he meets Bond face-to-face and his facial scar becomes visible to the audience.

Guardian Unlimited, "Bond Villains". 2011.

The discussion that followed from participants' viewing this image was one of the most surprising. Initially, P1 and P3 felt that this character looked "wise" and "pensive", and suggested that he did not necessarily look "bad". However, P4 interjected and stated that, "…looking at this I can tell…he is a bad guy." My response to this statement from P4 was to inquire what made him inherently think that way. P4 replied with an honest, yet (to my mind) alarming answer:

> "That scar that I see -- and like the way he is...looking. To me he looks angry or
>
> not happy… and that scar there…just shows that you --- and I know this is basically
>
> because of media and what I have seen before… but based on what I have seen and
>
> based on all the knowledge that I have --because of that scar [it] makes me think that he
>
> is a bad person."

The reason I found this alarming is that several participants agreed with this sentiment, and P3 felt that without the scar, Blofeld would look like "a business man….something that is not evil". My response to the participants was to inquire why Blofeld would no longer be seen as a "bad guy" without the scar on his face. P3 explained, "I know this is a stereotype…but [without the scar] maybe you would think of him as a nice guy who just happens to be caught without a smile"

As a result of these responses, several ideas emerged in my mind that will be addressed below. Specifically, I was left wondering what led to many participants seemingly to justify the idea that in order to be "normal", one could not have a facial difference. Secondly, the reality of the stigma that individuals with facial differences experience became acutely prominent from this discussion about Blofeld, as participants admitted to be judging this character based on how he looked.

Manipulated Judgements – The Media Impacts How We "See"

It is interesting that not only did P4 state that he feels this character is bad because of his facial difference, he also identified that in part, his response had been shaped by the media's influence over him. Research done by Farnall and Smith (1999) reveals that when viewers see representations of physical difference in television and movies, it is highly related to "perceptions of discrimination….and a greater likelihood of feeling uncomfortable with those with some types of disabilities" (p. 669). Further, Parashar (2006) remarked that "It is a well-acknowledged fact that advertising's images shape social attitudes for the majority of the population which receives its myriad inputs from

the media" (p. 13). Given that P5 is acutely aware of his facial difference, (and the subsequent negative experiences he has had over his life as a result), it demonstrates that even knowing about media's power is not sufficient to mitigate its influence and effects.

P5 also felt similarly; that something about the scar on this man's face inherently meant that he was bad: "…it is about the story, there is a whole story behind the scar --I guess without it he would just be a guy with a cat." It would appear even individuals who identify as having a facial difference can find it difficult to see someone with a facial difference as simply a 'normal' man. It almost seems as though the participants were struggling to see how this person could be 'normal' when he looks like he does. This interpretation from the participant relates back to the discussion about Two Face; whereby the story behind his facial scarring seemed to justify his villainous behaviour.

At this point in the focus group, I asked the participants to forget the character biography that I had provided them with earlier, and to instead dialogue simply about this image of a man. I made this decision because I felt that the group was feeling restrained by the fact that this character is a villain in James Bond, and many of them were trying to determine if he was "evil" because of the scar. As such, I wanted to determine their interpretation of this man simply based on how he looks.

> Me:- so let's talk about this isolated - if we just forget [the character], would he
> become someone's pensive wise old grandfather with a cat…?
> P4: "If he did not have that scar, he'd just look like an old guy."
> Me: "But the second we see the scar you immediately thought evil?
> P4: "It was evil…"

It must be acknowledged that it appears that I did engage in a leading question in this instance, but participants had previously used the term "evil" in relation to Blofeld before I did. This brief conversation caught me off guard, as I was not anticipating that the first half of the focus group was spent discussing how painful it is to be made to feel less-than others because of their facial difference, but the participants were now seeming to cast judgement on someone else based on the presence of a facial scar. P4 explained further:

> "…I completely admit I am judging him right now because of the scar…but yah based on like, media and everything, and how manipulated we are –[we are] automatically judging [him as] a bad person"

It is important to highlight the disconnect between participant's awareness of the effects of the media on their own self-image and the way they interpreted and viewed these images – which was based on the same usage of judgement and stereotyping. Specifically, P1 said earlier on: "…media is made to manipulate the way you feel" and P4 agreed: "…media clearly manipulates…so growing up, the thought of me having a facial difference…I thought I was bad and hated it…" and moreover, P1 explained "the repetitive cues that we see in the media...[leads to many people thinking] it is normal to judge…and that hurts because we have something different about ourselves". Despite these participants being aware of the negative impact of misrepresentation in the media, the media remains a strong influence over how *they* interpret facial difference on others.

Stigma

Interconnected with the judgements made by participants about the character Blofeld is the impact reality of stigma. Goffman (2009) defines stigma "as an attribute that is deeply discrediting" (p. 4) Coleman Brown (2010) explains that stigma can represent the social reality of a culture, and further, how people are understood in terms of relationships and roles; indeed, stigma often reflects the value judgements of a dominant group. If, as I have argued earlier in the Methodology section, people in the dominant group wish to avoid or eliminate the possibility of encountering people with undesired differences, then this group further asserts its power by determining which of these differences are or are not acceptable. Coleman Brown (2010) also argues that physical differences may be so severely stigmatized because, in most cases, the difference cannot be altered and can represent to some the idea of a 'deficiency' or 'distortion' of the body.

The context of time and place greatly affect the notion of stigma; what people find as desirable or undesirable may change depending on where and when you live (Coleman Brown, 2010). P2 shared that the definition and consequences of stigma related to her facial difference changes depending if she is in her hometown of Toronto, or visiting family in the Philippines:

"I go home to the Philippines every two years and something like a facial abnormality is really…unacceptable. It is just really different and is unknown in society…and every time I go home I feel like I am always getting stared at…even in the malls, buses,

everywhere - because it is not normal…whereas [in Toronto], I hop on the bus nobody

looks at me, nobody cares, I go to school, I go to the mall nobody cares so that is

something that I experience."

This quote from P2 links back to the discussion about Two Face and Blofled, in that

depending on the context (of history, place, and time) ones interpretation of facial

difference might change. However, there seems to be a fairly consistent reaction to facial

difference in mainstream media representations. The consistent theme present was that

every participant discussed the effects of stigma on their own lives. An example of these

experiences came from P4, who reflected on how stigma has infiltrated his life from a

young age: "…growing up, like the thought of me having a facial difference –I thought it

was bad, I hated it…"

I would argue that the social phenomenon that is stigma relates to 'othering' in

that they are both the result of a dominant group arbitrarily deciding what is or is not

'normal' or 'desired' at a particular time and place in the world. Similarly, Coleman

Brown (2010) believes that the use of stigma allows one group to feel superior over

another group. Related to the stigma of having a facial difference, many of the

participants shared that they often have been made to feel inferior based on how other

people respond to the way that they look. P3 explained how she combats the stigma

associated with her facial difference:

"…with a cleft, I have always been really smiley because I do not want you to think

that I am mean because of how I look…I know it sounds silly but …if you smile

67

a lot then [people] think 'they are not so scary or mean…[they're] happy".

It is so striking that this individual feels the need to smile in order to ensure strangers do not mistakenly see her as "mean" or "scary". This highlights the very fact that the media images we see on facial difference purposely shapes facial difference as something to fear. The reality is that the representations of facial difference extend far beyond the movies or images they are in; it impacts individuals in their everyday life, as they are negotiating (both consciously and subconsciously) with the judgements of facial difference that they know are present in our society. Perhaps this can explain why the participants decided to remove Blofeld's scar, as it gave them a sense that he would no longer be seen as "evil".

The group decided that they wanted to alter the image so that Blofeld was no longer an evil character from *Bond,* but rather an old man watching television. Their thought process pertained to the removal of his scar, in order to make the viewer see him as someone without a backstory, because there would then be "nothing defining about the picture". Meaning, rather than the viewer immediately seeing the scar and wondering about how it came to be, the viewer would not see any reason to question him and would see him as just "a man…with a cat".

Focus Group's Redone James Bond Villain

My Changes

As someone with a facial difference, I found the participant's decision as to how to change this image the most difficult finding of the research. As mentioned, the participants seemed to believe that in order for the character to be seen as "normal", his scar would have to be removed. I was very troubled that the participants with facial differences were unable or unwilling to see this character and other subjects of images in a positive or "normal" light until his or her facial difference was removed. I am using the word "normal" because I felt the decision of the group to want to see Blofeld as "just an old guy with a cat" and that, in turn, means to me that they could not see him as anything but "different" so long as he still had a facial difference.

It must be noted that in no way am I judging or blaming participants for their reactions and responses to the images discussed in the focus group. Indeed, there exists a tension within this research whereby I sought to value lived experience as knowledge, yet

I was troubled – even, at times, disappointed – by some of the responses from the focus group. However, this disappointment is a reflection on the larger macro structures involved in the social construction of 'difference', 'normal', and the resultant ways we (members in society both with and without a facial difference) are shaped to 'see' and 'understand' facial difference. As I mentioned earlier, I am only beginning to address my own interaction with my facial difference and the media's influence on my self-worth and identity. As such, it leaves me wondering what are the implications for people with a facial difference (including the participants) who have not had the same opportunity to develop a critical awareness of media representations? Again, I must emphasize this is not about blaming these individuals, but raising the issue of how this can be addressed.

In the discussion with participants as to how they wished to change this image, it was evident that they were determined to remove the character's scar. At two separate points in the discussion I found myself actively trying to get participants to see Blofeld as something other than an evil character; however, the group would not change their viewpoint. It had been my hope from the onset of the research that participants would want to actively critique the facial differences as seen in the media, and look for ways to showcase them in more positive or accurate ways. This, in itself, shows my own bias towards the topic, and the on-going battle I had as an insider navigating with my recent 'awakening' to media representations of facial difference as problematic. Nevertheless, this was not the case in this research and I am led to question what factors were involved in both my own reactions/responses and those of the participants.

Because my thoughts about this image were somewhat different than those of the participants, I believed a different type of change was required. Indeed, throughout this process, I was aware that the image was designed to portray the character as evil, and in order to convey this message it relied on negative stereotypes and assumptions of facial difference. The critical lens that I brought to the research differed from that of the participants, and I suspect that without such an understanding, I too would be quick to judge these characters (such as Blofeld) as implicitly evil because of how he looks. Even admitting this is quite difficult to me – but is vital to do so in order to recognize how powerful the messages received by the media actually are, even for those with a facial difference.

As a result, I felt it was necessary to leave Blofeld's facial difference as is, and to instead, re-cast him as a 'good' person. In a similar fashion to Two Face, my decision for this was to provide a stage for Blofeld to be seen as something other than evil, particularly when the participants' conversation about the image focused on his facial difference as the lynchpin to their interpretation of him as a villain. Indeed, I altered the image in such a way as to suggest that Blofeld and Bond are in an alliance, perhaps with Blofeld in the role of Bond's mentor, rather than his arch nemesis.

Ideally in my reworking, the image does depict the two men as friendly and trusting in one another. I tried to demonstrate this by situating the two men sitting together in a social setting, sharing a drink, and posing in an engaged manner. It is my hope that this suggests to the viewer that seeing an image of someone with a facial scar does not have to instantly lead one to the conclusion that the person is evil. I hope, too,

that when people see the original Blofeld image set alongside the participants'
transformation that they might come to understand that their perception of someone with
a facial difference as 'evil' is the result of stigma and negative judgement which have, in
large part because of media portrayals, infiltrated our belief systems for years.

Stephanie's Redone James Bond

Summary

A lot of information came from the focus group; some of the key messages include the following. The existing literature suggests that the messages we receive through advertisements, television, and movies play a part in our understanding and development of what we "know" of facial difference. I was surprised to learn that many of the focus group participants judged several of the characters we discussed based on their appearance. I found this to be puzzling, as I had pre-conceived notions that individuals with a facial difference (like me) would be equally critical of these current representations. The fact that they were not as critical as I anticipated leaves me to question just how influential the media is in creating and sustaining the idea that to have a facial difference inherently means you are "bad" and what is needed to change this.

Further, it would be interesting to investigate how individuals with facial differences in other parts of the world interpret both the images of facial differences they see in the media, and in turn, themselves. Are these representations similar or different to that which we see in Western society? If they are different, (and therefore, presumably more accurate or reflective of lived experiences) what attitudes surround facial difference there, and why has our society not picked up on these (perhaps) differing "understandings" of facial differences?

I also find that there is a problem in the fact that there are no rules or regulations to ensure appropriate representations of physical (and facial) difference are produced by the media. I wonder why there is not a policy similar to the Canadian content legislation;

I envision a policy similar to the Canadian content rule, which demands a certain percentage of television and radio programming be exclusively by Canadian content (CRTC, 2013). Without requiring a similar rule to ensure that physical difference is represented both regularly and appropriately, how else are we to put an end to the perpetuating cycle of harmful and misleading representations of this group?

Another key message that was produced from the research group relates to the importance of language, as it relates to representing facial difference. Indeed, research participants felt strongly that language was important to address: using appropriate words to label and define facial differences is necessary to provide the viewer/reader with an education on the topic, as well as to contribute to a meaningful representation of the facial difference. The literature illustrates that through the use of certain words and images, certain stereotypes about physical (facial) difference are reinforced. Doing so can assist in the deconstruction of misleading judgements or assumptions that are often connected to the current representations we see for facial differences.

Implications

Why does any of this matter?

This research has identified the need for more attention to be paid to how facial difference is represented in the media. The individuals with facial difference participating in this study emphasized just how much these media representations negatively impact their sense of self-worth: this appears to be a result of how these media representations deviate so significantly with what society understands (and values) as "normal".

Appreciating the main points that have derived from this research is important for social workers, as this profession is not immune to these media representations of facial difference (Fudge Schormans, 2011). Given this research revealed that even individuals with facial differences are influenced by what they see in the media, it can be understood that social workers might also be influenced by such representations. As such, it is important to recognize that greater attention must be paid to the oppressive structures of the media, and the pervasive medical model of disability that are dominant in our society.

Social workers need to acknowledge that the representation of facial difference in the media is a social justice issue. As both a social worker and a person with a facial difference, I feel it necessary to rally allies (both with and without facial differences) in an effort to create awareness of these representations and their effects, and of the need to confront the producers of such. Doing so is a means of working towards a more inclusive and appropriate understanding of what it means to have a facial difference, and how inaccurate representations can be quite harmful to those with a facial difference.

Moving in the Right Direction

There has been some recognition on the part of the media that there is in fact a lack of representation of facial and physical difference in Canadian television (Canadian Broadcasting Standards Council, 2008). In 2004, the Canadian Radio-television and Telecommunications Commission (CRTC), created an action plan to assess the current (lack of) representation of physical "difference" (and disability) in the media.

Some efforts have been made to address this, and it has been done, in part, by casting actors with physical differences in films, television, and advertising (most frequently in commercials) (Jaeger & Bowman, 2005; p. 106). However, this small step has not yet accomplished the desired results of accurate and appropriate portrayals of facial difference. Specifically, the very fact that macro corporations like Disney and Lego rely on facial difference to emphasize their character in the *Lone Ranger* as a villain demonstrates that the long-standing stereotypes of facial differences remain as something to capitalize on, and resultantly, further marginalizes and stigmatized this group of people.

Dahl (1993) remarks:

"Although personal interaction is the most effective medium for conveying the personal experience of disability, the mass media can be an effective vehicle for bringing about greater understanding, and a consequent gradual change in public perceptions, of people with disabilities" (Introduction, par. 1).

Knowing this, social workers need to challenge the negative portrayals of facial difference that is built into our language, media, and values. While we are beginning to see more representation of physical disability in popular culture, we need to be wary of

tokenistic uses of these characters, as the notion of "difference" and how it is negatively

represented can easily continue to remain ignored or overlooked.

There is merit to these developments when the work is done in "consultation with

national and international disability organizations, local disability organizations, and

individuals with disabilities themselves" (Jaeger & Bowman, 2005; p. 107). In particular,

the benefits that could come from this include increasing support for disability rights.

Ways to achieve this could include, shared learning, education in media rights programs,

and collaborating with people with disabilities. For example, Jaeger and Bowman (2005)

remark that positive changes to societal attitudes about disabilities stem from

> "the writing of scholarly and popular personal narratives by people with disabilities,
>
> as well as by the appearance of magazines, web sites, and other publications devoted
>
> to issues of disability. These publications have helped to increase awareness about
>
> disability, to personalize disability for people who had not previously put a human face
>
> on it, and to increase public support for disability rights" (p. 4).

Having heard first-hand from individuals with facial differences, it is clear to me

that social work researchers, educators, practitioners and media communications policy

makers must work together to confront the purposeful and harmful practice of negative

portrayals of facial difference in the media. When, as mentioned, corporations like Lego

or Disney actively create and promote villains based on their facial difference in 2013, we

cannot stand idly by and not confront this. It is not acceptable, and we cannot allow the

justification of such descriptions or role placements as coincidences or as having no

meaning; as I believe there is often negative intent behind these choices.

A small, but important example of how change is possible can be seen with my recent interaction with Lego. After seeing their promotional materials declaring the character with cleft lip and palate as "soulless", I wrote them a letter explaining my concerns (see Appendix O). Within a week, I heard back from this corporation, and they had changed the description of the character to no longer focus on his physical appearance (see Appendix P). To be sure, this change did not come directly from my letter, but indeed from the many people who united together and expressed their concern for this injustice and inaccurate portrayal. More attention is needed to issues such as this, coupled with further research to extrapolate how impactful the media is on people with facial differences, as well as what (seemingly small but meaningful) changes could be made to alleviate some of these issues.

There is merit to this, as these representations will benefit from further research and consultation (Jaeger & Bowman, 2005), particularly in collaboration with individuals with "differences" themselves. Indeed, I see a lot of value in including those with lived experience to contribute and shape a more accurate representation of characters with facial difference in the media; this can be done through the notion of shared learning. McKenzie and Wharf (2010) suggest that, "the concept of shared learning is perhaps the most important contribution of inclusive approaches. Shared learning breaks down misconceptions that often stand in the way of reaching agreement, it brings in the perspectives of the front-line practitioners and of service users, and in so doing enriches the information at the policy table" (p. 147). Furthermore, I agree with Jaeger and Bowman's (2005) suggestion that social barriers could be broken down when and if

"high-profile, award-winning movies were to provide accurate, positive, and representative portrayals" (p. 106) of "difference", as opposed to the continuation of overused and outdated stereotypes that we see today.

Possibilities for Social Work Education

It is important to note that attention to media representation – including that of those with facial difference – can have a positive impact on preparing social work students to be more critically aware of this topic. For example, students can critically discuss media representations and moreover, can consider the impact of such on their own values, and on their own understandings of marginalized groups. This research has led me to ask myself, what comes first: an inappropriate representation in the media which then leads society at large to develop misconceptions and stereotypes about people with facial difference? Or society's pervasive and negative ways of looking at and understanding people with facial difference s leeching into popular media? Hartnett (2000) suggests that societal attitudes and the media are very much intertwined: "The social inequality is both reflected by and upheld by the media. As society's attitudes change, the media will reflect those attitudes". (p. 28).

Conversely (and similar to Jaeger and Bowman's thoughts), the media should be called on to play an active role in challenging society's fear and misunderstanding of disability by consciously seeking to portray characters who are "different" in regular, appropriate, and more accurate representations. Indeed, the benefits of including more accurate and also numerous and more diverse portrayals of individuals with facial differences in the media are twofold. First, it may help those with a facial difference to

construct a healthier and valuable image of themselves, and second, it may create a society that is more informed and educated on the topic of facial differences. Indeed, as pointed out by the research participants, education works to break down stereotypes, intolerance, and devaluation. Furthermore, greater attention to disability, and the experiences of people with disabilities (including facial difference) could be included in discussions of media representations and social understandings of other marginalized groups.

Synnott (2006) points out the irony that "the ugly, the disabled, and racial and ethnic minorities are stigmatized, marginalized, and excluded, despite our egalitarian, democratic and meritocratic beliefs and ideologies" (p. 169). The differing models used to understand disability in our society illustrate how we create an understanding of whom and what gets valued, and or marginalized. We must recall how the ongoing power of medicalized ideas of disability inherently work towards pathologizing people with disabilities. This combines with the persistent lack of regulation over media representation of disability that means these representations are not changing to reflect the actual lived experiences of individuals with disabilities.

Since there appear to be no regulations in our media and cultural institutions ensuring that those with facial differences have meaningful involvement in the creation of accurate representations of people so labelled in television or film, I am left wondering why it seems that the issue of representation of physical disabilities do not matter to society at large. Specifically, the Canadian Broadcasting Policy only requires programming objectives that create programs accessible by disabled persons (Dewing, 2011) – it does

not require programs to ensure they are including individuals with physical disabilities

behind the scenes or in front of the camera to ensure accurate and quality representations.

I am suggesting that social work students strive to adopt a Critical Disability lens in

order for them to respond more critically, not only to media representations of disability,

but also to their own values and assumptions about people with disabilities. This lens

would also be useful for social work research and practice when working with individuals

with disabilities, including those with facial differences.

If this is accomplished, social workers can promote and demand a shift from the

medical model of disability, towards a new perspective that sees "differences" as a flaw

within the macro system, rather than within the individual. Specifically, we need to

challenge neo-liberalism's approach to "difference" and disability which views this issue

as misfortune or bad luck (Pothier & Devlin, 2006).

Possibilities for Social Work Research

More research is certainly needed in order to further extrapolate how impactful the

media is on people with facial differences, as well as what changes could be made to

alleviate some of these negative impacts. Utilizing CDT in this work would be beneficial

as it would ensure the work focuses on addressing the social structures as the site of

change, rather than the individuals with facial differences. I would suggest that such work

be conducted with qualitative research methodologies, as the present research revealed

that paucity exists in this regard. The target audience can include a myriad of people:

policy makers, television and movie producers, and medical professionals (to name just a

few) in an effort to provide education about the importance of appreciating lived

experience as knowledge.

Possibilities for Social Work Practice

When marginalized groups are given the same message over time, either subtly or

overtly, that they are not valued as an equal citizen with opportunities to voice their

opinion, it can create feelings of self-blame. As revealed by this study, this can and does,

ultimately lead some to understand their oppressed world as "normal", and it might feel

like there is nothing they can do to alter it for the better. Callahan explains how "We are

often inclined to personalize our experience and frequently blame ourselves for our

failings." (2010, p. 169). This is a frightening reality, as it highlights how dangerous it is

when ways of knowing are not questioned or challenged. While this has implications for

the aforementioned suggestions of using education and research as a means of working

towards larger societal change, it also has ramifications for people with facial difference

on an individual level.

Related to the issue of genetic pre-screening, the social work profession could

play a larger role in conversations and or counselling with parents. In truth, social

workers are not always involved in such conversations about prenatal diagnoses of facial

difference, but that is not to say the profession should not be more actively involved.

Perhaps in the very least, social workers could do more to educate medical professionals

about the importance of communicating with parents faced with a prenatal diagnosis of a

facial differences in a way that does not merely focus on the (seemingly) negative aspects

of surgeries required to "fix" their child, and to support connections to other families raising a child with facial difference that provide alternative and positive views.

Additionally, social work practice with people with facial differences might incorporate efforts to support this group to recognize the social construction of facial difference as it is played out in the media. Moreover, how such representations can (and do) negatively impact one's sense of self. Calling on a CDT lens may be useful: it was not until I gained an appreciation for this theoretical framework that I was able to appreciate the problematic ways in which physical difference is "understood" in our society.

It can be seen that the current situation regarding the representation of facial difference within advertisements, television, and films is one that has numerous negative effects for people living with a facial difference. The impact of these representations can hit those with a facial difference quite hard, as media consistently depicts "difference" as something to pity, to be scared of, or needing to be overcome (Covey, 1998). "Whether media is making, reflecting, or re-enforcing the message, it is clear that in the [North] American context such images are transferred from product to person" (Phillips, 1990; p. 850). The media contributes to the 'othering' of those with a physical disability – including facial difference - by way of creating distinctions between "normal" and "different", and such social classifications are indeed disempowering (Jaeger & Bowman, 2005). This reality should matter to social workers, as we strive to recognize the various power imbalances that impact marginalized groups.

When we live in a society that has historically had negative and destructive reactions to those with facial differences, it is vital to acknowledge the role that media

plays in perpetuating these harmful ways of viewing "difference". While it can be

contested just how much of a role the media plays in shaping our attitudes on this topic,

there is growing recognition that the power of the media on societal attitudes is

significant: as I noted previously, the CRTC *now* recognizes the influence of broadcasting

on its viewers. I have given an entreaty in this thesis to the social work profession to

support efforts to use visual media to create more respectful and acceptable representation

of facial difference. This is a necessary step towards positive change, as we know that

"Broadcasting is…a powerful medium to reinforce…stereotyping and can be equally

powerful to correct it" (Dahl, 1993; Creating an "Average" Typification of the Disabled

section, paragraph 2).

If we continue to allow images of facial difference to be produced only by those

without an actual understanding of these realities, then we will not be able to alter the

ways that persons with facial differences have been represented in society (through

various media types) for hundreds of years. Nor will we be able to effectively work to

alleviate the impacts of such on people with facial differences themselves. When

characters in books, television and film are negatively marked by their difference, they

can become caught in an endless loop of tautological reasoning that comes to make

'perfect sense' to their audiences (Franks, 2001) – including people defined as

"different". This means that the media serves to undermine the real identity of

"difference" in favour of a view that actually oppresses and perpetuates stereotypes.

We must recognize that social work professionals can be allies in addressing this

social justice issue, but they can only enact positive change once it is recognized that

social workers are also active recipients of these representations of facial difference. Therefore, it is imperative that social workers exercise regular critical self-reflection in order to understand how media representations have impacted their own values and assumptions about this group of people.

It is my hope that this is only the beginning of a long conversation about media representation of facial difference, as there is still much to learn and much more work to be done. While the media at large cannot be blamed entirely for how one develops self-esteem and a self-image, it cannot be ignored that it can have a valuable part to play in breaking down long standing beliefs about facial difference. It would be beneficial to continue the conversation with those who have lived experiences to truly grasp how their family, friends, medical professionals, and strangers can all work together to improve representation. Indeed, participants had a lot of suggestions as to how accurate and appropriate representations of facial differences could be implemented in our society, and why this is so pertinent.

It would also be worthwhile to re-visit this discussion with participants to discuss what their thoughts and views of representation of facial difference in the media are now, as many of the people in the focus group stated they had never consciously thought of whether or not media representations impacted them.

Understandably, not all individuals with a facial difference are connected to support organizations or the programs that they were once involved in no longer work with them after childhood. Nonetheless, creating an awareness of this very real issue and calling on practitioners to challenge these hegemonic practices would be a positive step towards

debunking the notion that to have a facial difference means you are "abnormal" or

"wrong" in some way.

Appendix A: Recruitment Poster

McMaster University

PARTICIPANTS NEEDED FOR RESEARCH EXPLORING
MEDIA REPRESENTATION OF FACIAL DIFFERENCE

We are looking for volunteers (18-30 years) who identify as having a facial difference to take part in a study.

You would be asked to:
-Participate in a workshop with other individuals who identify as having a facial difference
-Participants will engage in analyzing media and co-creating new images

In appreciation for your time, you will receive a $25 gift card!

For more information about this study, or to volunteer for this study, please contact:

Stephanie Chatland
School of Social Work

Let your voice be heard!

Refreshments will be served!

mcmaster.ca

This study has been reviewed by, and received ethics clearance by the McMaster Research Ethics Board.

Appendix B: Article for *Aboutface* E-Newsletter

Stephanie Chatland is a student at McMaster University and has been connected with Aboutface International for several years. Stephanie has connected with us regarding her research interests, and has asked us to pass on information about her study. This research is part of her Master of Social Work program at McMaster University.
Stephanie is inviting you to take part in a two-day group discussion of people 18-30 years old (with the group made up of 6-8 individuals) from the greater Toronto area. This research will take place on a weekend, at a central location for most participants. She will work out the details with you as the recruitment process unfolds.
Having been born with bi-lateral Cleft-Lip and Palate, I have lived my life avoiding mirrors, and negatively comparing myself to the images of beauty I saw in movies, television, and advertisements. My personal experience with being "different" has led me to an interest in analyzing the role of media in representing facial difference.

I am currently completing my Masters of Social Work degree at McMaster University. My professional role as a Community Mental Health Worker in Hamilton has instilled in me many research interests. However, they were not able to trump my desire to pursue researching something near and dear to me: living with a facial difference. The small literature review I have done so far on the topics of facial difference, and physical disability has highlighted a need to hear from those with lived experience in an alternative way from surveys and self-assessments. It is my hope that co-creating a research space for individuals who identify as having a facial difference will allow for voices to be heard in a different (and meaningful) way.
The purpose of this research will be to hear from young adults living with a facial difference in order to explore media's representation of facial difference (in terms of good versus bad, and ugly versus beautiful). I hope to learn whether or not the way society understands these ideas has impacted those with a facial difference. Throughout history, those with a physical difference have been pushed to the fringe of society and given second-class citizenship status, resulting in the inability to contribute or control the message that has been generated for society to develop an understanding of their difference from. In the critical disability literature, many scholars are emphasizing how a large part of our society is exposed to views of difference almost exclusively through mass media. Commercial advertising and the popular media establish and re-enforce such notions, powerfully influencing social attitudes and behaviour toward persons with physical differences. The problem is that these values have permeated our literature for centuries, and have done so without being loudly challenged. For example, one can look to characters such as The Hunchback of Notre Dame, Frankenstein, Captain Hook, Long John Silver, Mr. Hyde (to mention a few) who were all understood as villainous in relation to their physical difference. I am inviting you to participate in a discussion about

these prominent images, as well as to have the chance to re-create the images in a way that you see as more accurate or appropriate.

It is my hope to have participants engage in a two-day workshop in May, 2013 in the GTA. Refreshments and compensation will be provided. If you, or someone you know is interested in participating, or would just like to learn more about the research, please contact me: chatlas@mcmaster.ca

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:
McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
Gilmour Hall – Room 305 (ROADS)
E-mail: ethicsoffice@mcmaster.ca

Appendix C:

No Change By Participants / No Changes By Me

Shrek

Appendix D (1)

No Changes By Participants / Changed by Me

Disney's Hunchback

Appendix D (2): Stephanie's Redone Disney's Hunchback

Appendix E (1)

No Changes By Participants / Changed By Me

Two Face

Appendix E (2): Stephanie's Redone Two Face

Appendix F

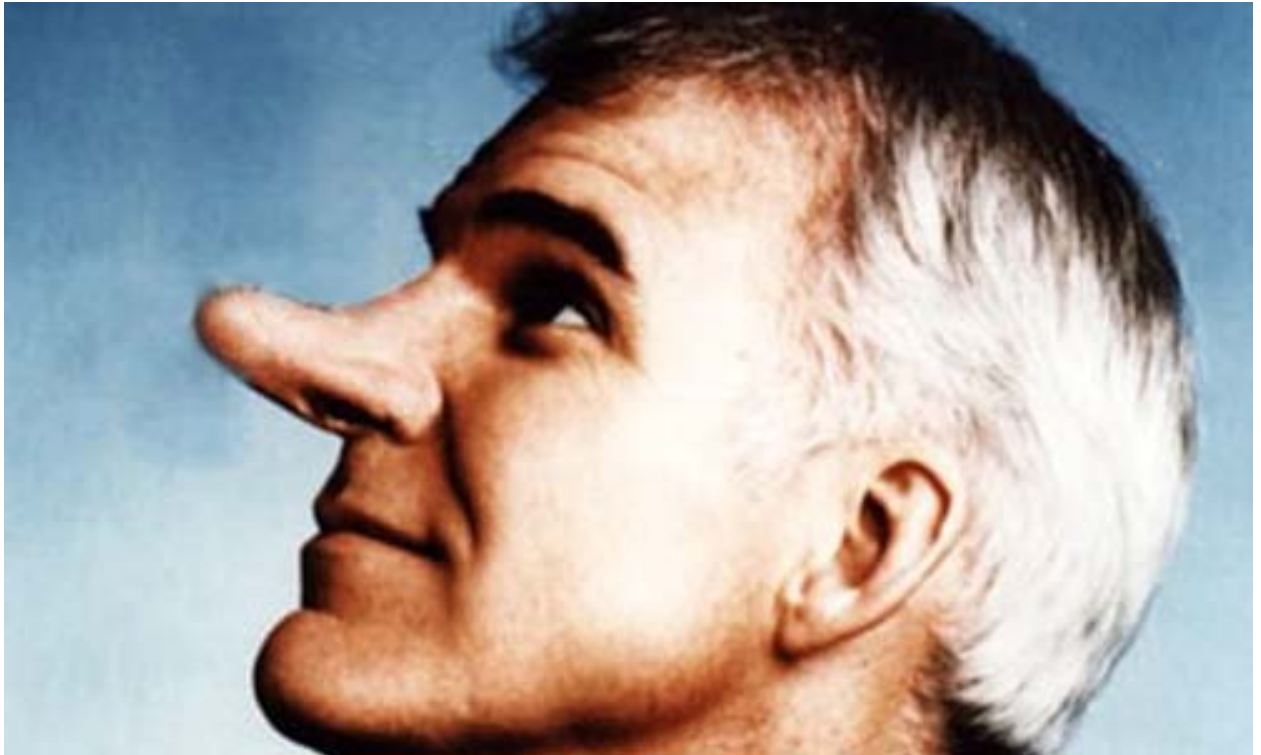*No Changes By Participants / No Changes By Me*

Boardwalk Empire

Appendix G (1)

No Changes By Participants / Changed By Me

Roxanne

Appendix G (2): Stephanie's Redone Roxanne

Appendix H (1)

Minor Changes By Participants / Changed by Me

Mask

Appendix H (2): Participant's Redone Mask

Appendix H (3): Stephanie's Redone Mask

Appendix I (1)

Changed By Participants / No Further Changes By Me

CNN Banner

Appendix I (2): Participant's' Redone CNN Banner

Appendix J (1)

Changed By Participants / Changed By Me

Birth Defects Ad

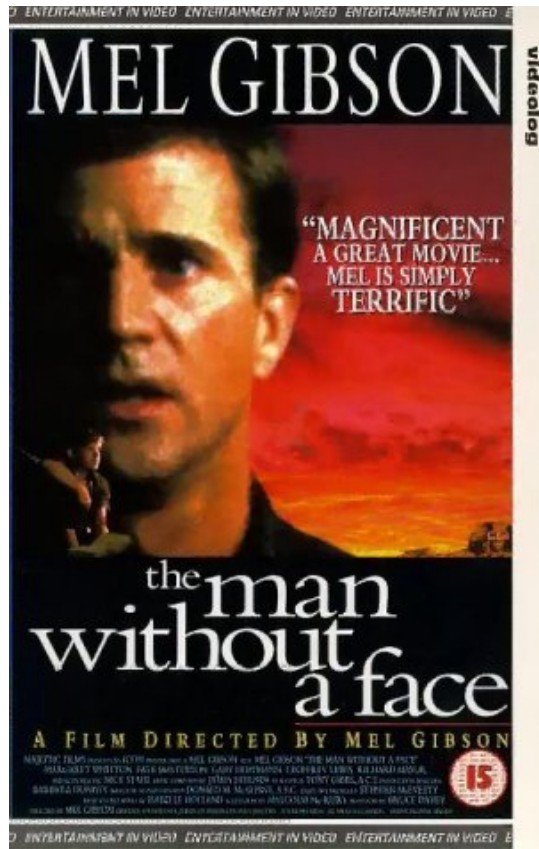Appendix J (2): Participant's Redone Birth Defects Ad

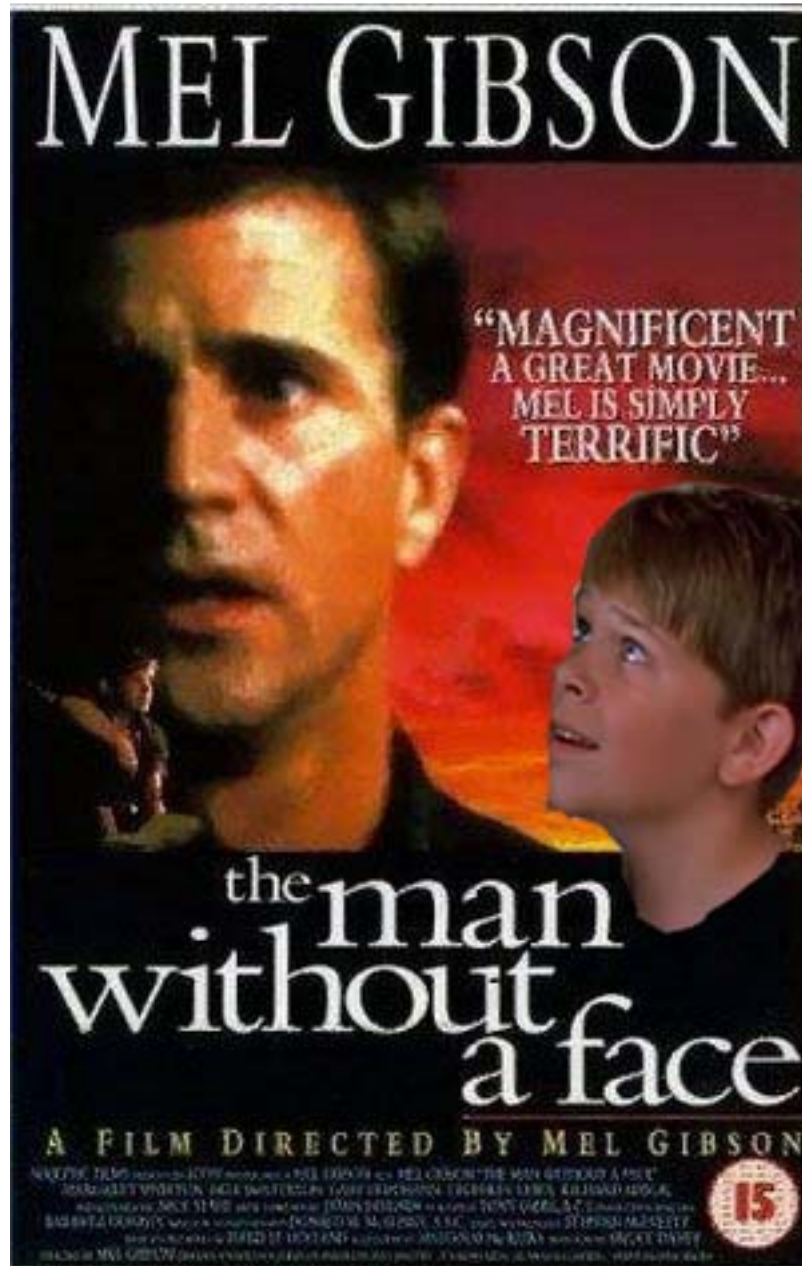Appendix J (3): Stephanie's Redone Birth Defects Ad

Appendix K (1): *Changed By Participants / Changed By Me*

Man Without a Face

Appendix K (2): Participants' Redone Man Without a Face

Appendix K (3): Stephanie's Redone Man Without a Face

Appendix L (1)

Changed By Participants / No Further Changes By Me

Harry Potter-Villain

Appendix L (2): Participants' Redone Harry Potter-Villain

Appendix M (1): *Changed By Participants / Changed By Me*

James Bond-Villain
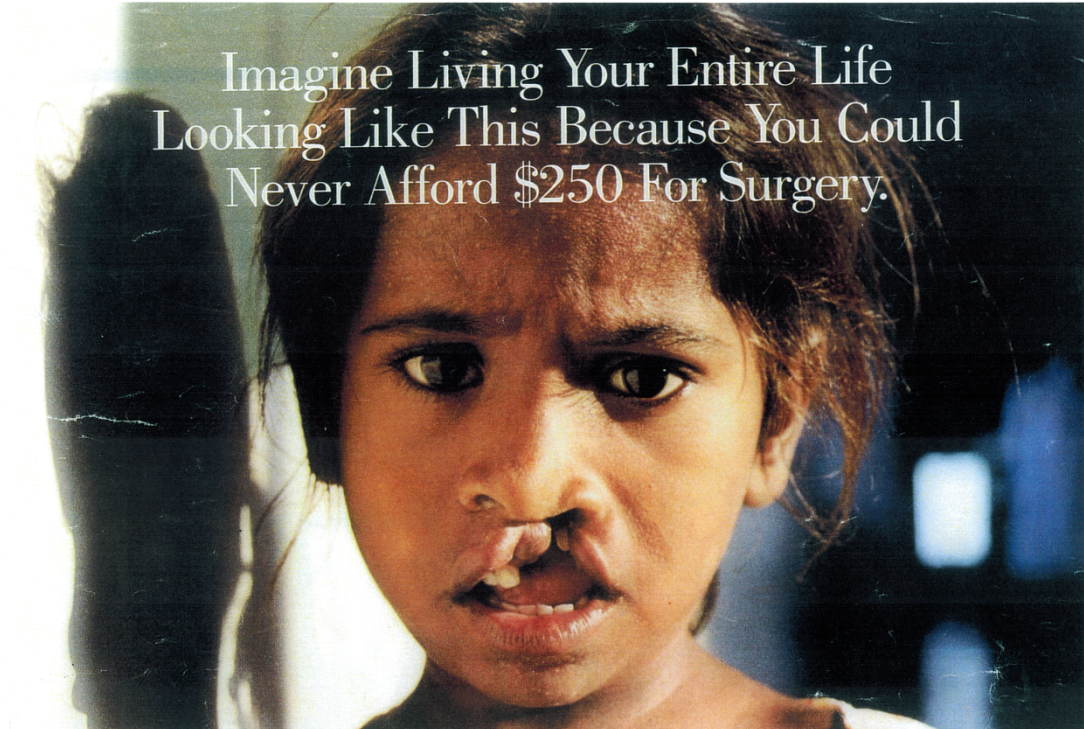
Appendix M (2): Participant's Redone James Bond-Villain

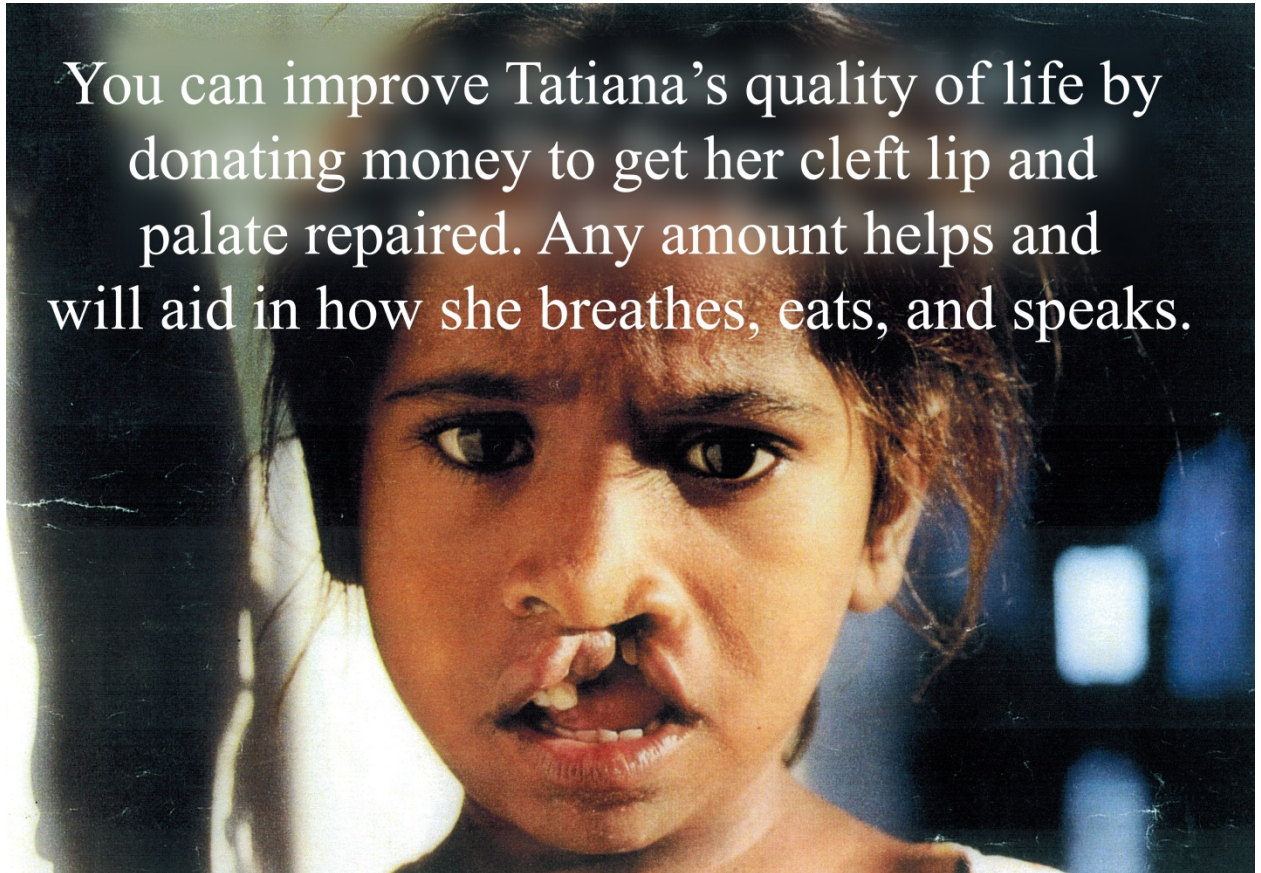Appendix M (3): Stephanie's Redone James Bond-Villain

Appendix N (1): *Changed By Participants / No Further Changes By Me*

Cleft Lip and Palate Ad

Appendix N (2): Participant's Redone Cleft Lip Ad

Appendix O – Complaint letter to Lego

July 26, 2013

Hi there
I am writing to you with a serious complaint about the character (villain) Butch Cavendish in The Lone Ranger.

Currently, I am doing research about how media representation of facial differences impacts those with birth defects (such as Cleft Lip and Palate). I am so horrified that you are describing this character as a villain (and "soulless") as a result of his cleft lip. How did you not given any thought or consideration to how this would negatively impact children (and adults!) who have cleft lip, and are left feeling that something must be wrong with them?

As someone whose family has spent decades purchasing Lego products, I must advise you that I will no longer be a customer.

I hope you seriously reflect on this decision, and avoid perpetuating stereotypes and myths in the future. It is not acceptable to describe this character as evil based solely on how he looks.

Why not consider having a character with a "difference" as is -- I would happily support a character who had cleft lip, but was not cast as evil and made to feel ashamed of their perceived "difference".

 I will also add that I was born with a Cleft Lip and Palate, and I do not think that this reality means I am "soulless".

Sincerely

Stephanie Chatland

Appendix P – Reply from Lego re: The Lone Ranger

From:**LEGO Service** (legoservice@lego.com)

Sent: July-27-13 11:48:01 AM

To: ███████████

Dear Stephanie,

Thanks for getting in touch with us.

I'm sorry to hear you're unhappy about the depiction of one of the
characters in our new LEGO® The Lone Ranger™ sets. We are grateful to
you and others for making us aware of the insensitivity of the wording
we used and we have removed it from our website. Thank you for taking
the time to give us this feedback.

Thanks again for getting in touch. We're always pleased to receive
feedback from LEGO fans! If you could take a moment to complete a four
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