

FACE EQUALITY INTERNATIONAL

Visible Difference & Disfigurement in the Arts



**A Position Paper on
the Inclusion of the
Visible and
Facial Difference
Community**

Compiled by activists and organisations from across the global face equality movement to call upon film, TV, theatre and creative industries.



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Who are we?

A unique Alliance of worldwide NGOs, charities and support groups.

Our vision is for the global facial difference community to live freely, without indignity or discrimination.

In order to achieve our vision, our mission is to position face equality as a social justice movement.



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Introduction

Around the world, millions of people have a visible difference, a term which indicates a mark, scar, or other condition that affects bodily or facial appearance. Approximately 10% of the population has a facial disfigurement that often interferes with their ability to lead a life free of prejudice and discrimination. Though medical and legal settings have historically used the term “disfigurement,” or “deformity”, visible difference or facial difference can be more neutral, universal and inclusive terms to use.

For many years, marginalised groups have advocated for better media representation. Documentaries such as *Disclosure* (2020), *CinemAbility: The Art of Inclusion* (2012) and *Miss Representation* (2011) have exposed harmful stereotypes and patterns of representation. We know more than ever the positive impact of accurate and empowering representation onscreen for marginalized people, but portrayals of people with visible differences have a long way to go.

In the arts, all too often, facial or visible differences are employed as a visual shorthand to indicate a character is psychologically or morally damaged. Characters with scars and other visible differences are cast as evil villains, pitiful victims, and renegade vigilantes. Their stories overwhelmingly center shame, bitterness, and rage.

This has serious consequences as people with visible difference navigate a world that has been taught to fear anyone who looks different. People with visible difference face challenges in school, relationships, careers, mental health, and more. All of these barriers are heightened by poor media representation, which reinforces a negative bias towards people with disfigurements.



Individuals and organizations such as Face Equality International, Phoenix Society for Burn Survivors, and Changing Faces UK, have long campaigned for a shift in representation and investigated the impact of media representation on individuals with visible differences.

“Media representation can truly shape societal attitudes for the better; when harnessed correctly. The facial difference community deserve to have their true, multi-faceted, real-life stories told. This is a critical issue for Face Equality International, and so we will do all we can to turn the tide on the disproportionately negative representation of facial difference; something we currently see all too often.”

Phyllida Swift, CEO of Face Equality International

Facial Difference in the Arts

“Today, the world’s great storytellers aren’t always telling the story of the survivors I have had the pleasure to know. ... Survivors, as we know them, have great strength, compassion, and a sense of community that the world needs to have more insight into. They need a bigger platform to show the great things they are doing and see them for the people they are — not the villains sometimes portrayed in film, literature, or television.”

Amy Acton, CEO of Phoenix Society for Burn Survivors

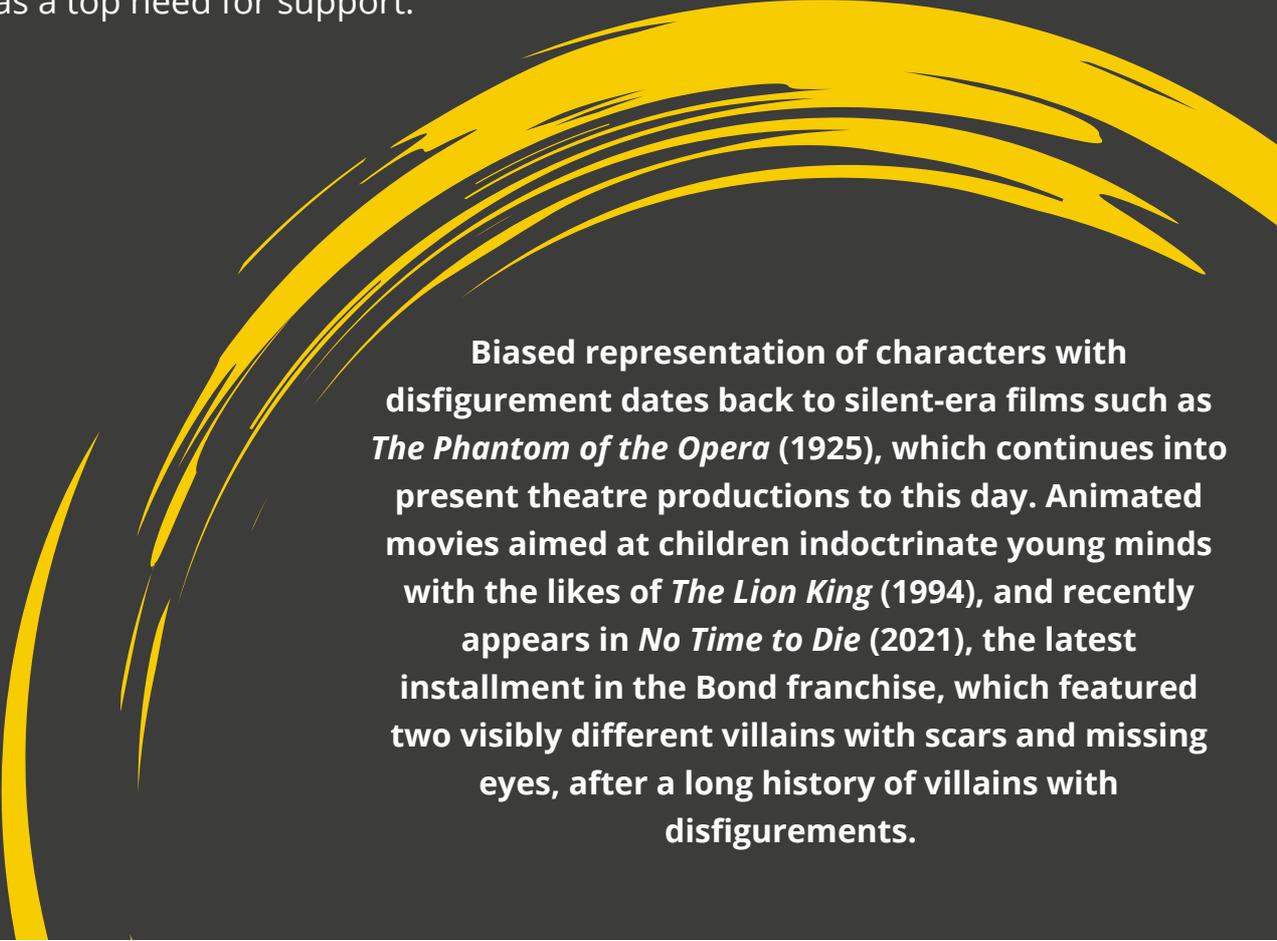
“I can’t recall seeing an empowering portrayal of a burned person. Unfortunately, it’s mainly been villains/evil characters... This makes me feel like people with scars and burns are unwanted, unloved, and unequal in society.”

Angie McKenzie, burn survivor

“Most people make the majority of their life acquaintances with disabled people only in film, television, and literature” (Snyder & Mitchell, 2006, p.181.)

A 2021 study from Changing Faces found that, “only 1 in 5 people with a visible difference have seen a character who looks like them cast as the hero in a film or on TV. Only 15% have seen someone with a visible difference playing the love interest on screen, while 39% have seen someone with a visible difference cast as the villain or ‘baddie.’”

In a 2022 survey of the burn community, Phoenix Society for Burn Survivors found 59% ranked “burn survivors & the media: changing the portrayal of the survivor” as a top need for support.



Biased representation of characters with disfigurement dates back to silent-era films such as *The Phantom of the Opera* (1925), which continues into present theatre productions to this day. Animated movies aimed at children indoctrinate young minds with the likes of *The Lion King* (1994), and recently appears in *No Time to Die* (2021), the latest installment in the Bond franchise, which featured two visibly different villains with scars and missing eyes, after a long history of villains with disfigurements.

For almost one hundred years, movies have cast scarred characters in different versions of the same roles:

1

VILLAINS

This stereotype is the most common characterization, with dozens of examples over the past century including iconic “baddies” like The Joker, Darth Vader, and Freddy Krueger. For more on film villains with facial difference, check out this [NPR feature](#).

2

VIGILANTES

These characters are misanthropic and morally gray. Outcasts and antiheroes, examples include Harry Potter’s Mad-Eye Moody and the titular characters of *V for Vendetta* (2005) and *Deadpool* (2016).

3

VICTIMS

These characters lacking agency and autonomy often need to be rescued. *Black Widow* (2021) featured this archetype with secondary antagonist, Antonia Dreykov/The Taskmaster.

4

OUTCASTS

Characters that are forced to hide away from society include the likes of *The Hunchback of Notre Dame* (1996)

Each of the above archetypes tap into different mistaken ideas about people with facial differences, but they perpetuate the same damaging lie: these individuals do not belong. These characterizations send a message that people with visible differences are a disruption to society and incapable of belonging to a community.

Characters with facial differences often self-isolate, coming across as their own worst enemy as opposed to the real-life reality where people are marginalised and discriminated against in society. Often characters are portrayed without even a single loving relationship. Their shame is a defining personality trait, often driving them to conceal their faces with masks.

This tees up another common storytelling device: the dramatic reveal, a device used in *Wonder Woman* (2017). In a moment meant to shock and unsettle the audience, a character reveals a facial difference, often by removing a mask. With this technique, media creators are framing facial differences as abnormal and surprising, encouraging audience members to recoil in horror and reinforcing the idea that facial differences should be covered up.

Disability Includes Disfigurement

Under the Americans with Disability Act and the UK Equality Act, people with facial disfigurements have protections afforded to people with mental and physical disabilities.

When it comes to onscreen representation, it can be helpful to remember scars and visible differences are a type of disability in the eyes of the law.

There are limited resources specifically dedicated to characters with visible differences, but much can be learned from the diversity and inclusion efforts around the representation of disability and other marginalised identities in media.

REAL WORLD IMPACT

“What is Beautiful Is Good”—Especially in Hollywood

In 1972, a psychologist named Karen Dion and her colleagues investigated a stereotype they called “what is beautiful is good.” This phenomenon is the well-documented association of physical attractiveness with positive social and personality characteristics, along with the expectation of better life outcomes. Though Dion was the first to put a name to it, the bias can be traced back for centuries and continues to be evidenced in implicit attitudes tests in recent years demonstrating the ‘disfigured is bad’ bias. (Hartund et al, 2019)

Using the American Film Institute’s list of 100 Greatest Heroes and Villains, researchers at the University of Texas found that 60% of the all-time top 10 American film villains have skin conditions including alopecia, facial scars, verruca vulgaris, and bulbous noses. In contrast, 0% of the top 10 heroes have similar conditions.

In 1999, another study was conducted: “Are the beautiful good in Hollywood? An investigation of the beauty-and-goodness stereotype on film.” In a sample taken from 5 decades of top-grossing films, attractive characters were portrayed more favorably than unattractive characters. After viewing biased films, participants were asked to rate applications of prospective college students. Despite all other qualifications being equal, participants gave more attractive applicants higher scores.

In 2010, another study titled “Do animated Disney characters portray and promote the beauty-goodness stereotype?” performed a similar assessment on Disney films using the same parameters. They found that children who watched a Disney film with an attractive bias preferred the attractive child over the non-attractive child as a friend.

In 2021, Changing Faces research conducted by Savanta ComRes found that three quarters of respondents (74%) thought popular culture was changing to be more inclusive, but that people with visible differences were being left behind. The same survey also reported the long-term impact of the lack of representation on people with visible differences, with a third having low levels of confidence and 2 in 10 having low self-esteem.

“Film, TV, theatre, advertising, and literature exclude or misrepresent an entire population of people with facial disfigurements. Continuing to stereotype us as villains, outcasts, pathetic, pitiful characters, or the subject of medical stories perpetuates stigma and prejudice. As Former President Barack Obama said, "It's hard to be what you can't see." Portraying people with facial disfigurements as confident and capable would help change negative attitudes and misconceptions”.

Charlene Pell, burns survivor and Founder of Facing Forward

A 2022 study from ChatLab (Penn Center for Neuroaesthetics), the impact of positive representation is proving equally powerful. After measuring participants’ implicit bias against faces with visible differences, researchers emailed participants images of a person with visible difference accompanied by a short, positive story about that individual. After just one week, the participants’ bias was measured again—and it had decreased significantly.

Living with Visible Differences

In 2020, Changing Faces UK published independent research which revealed:

- Seven in 10 people experience negative behavior such as stares, abuse, and bullying because of how they look.
- Over a quarter (28%) of people with a visible difference have experienced a hate crime.
- Almost half of those who have experienced negative behaviors say they have lost self-confidence.
- Over a third (35%) say they now feel anxious when they go out.
- Over a quarter (27%) say their treatment has had a negative impact on their mental health.

In 2022, AboutFace Canada published findings that echo similar experiences from the facial difference community in Canada which focused on workplace experiences:

- Around 3 in 5 people with facial differences have been negatively impacted in a working environment:
- 51% experienced staring or gaping from co-workers
- 50% had uncomfortable and/or difficult experiences during recruitment
- 43% felt there was a lack of opportunities or career progression
- 36% experienced bullying or harassment

“Acting has always been a therapeutic experience. It has helped build up my confidence, helped with my anxiety by playing characters outside of my comfort zone and found the joy of telling stories to others to make them feel and connect to something. On stage, I am not Crystal, who gets stares or sympathetic looks from the outside world. I am entirely different, and for only two hours, I can convince an audience that I am a love interest, villain, superhero, or so much more.”

Crystal Marshall, Actress and FD Activist

Beyond the Numbers

Data can only tell us so much, especially given the lack of comprehensive research regarding the experience of individuals with visible differences. Explore these personal accounts for a more nuanced understanding of the real-world impact of biased media representation:

-  [I'll Give You Something to Stare At, TEDx by Phyllida Swift](#)
-  [Taking Centre Stage by Professor Jaz Gray](#)
-  [I Am Not Your Villain featuring Changing Faces UK media champions](#)
-  [Challenging Representations of Disability in Film by Adam Pearson](#)
-  [The Phantom, Darth Vader, and Me by Dr. Lise Deguire](#)
-  [Me, A Monster? by Michelle Anderson](#)
-  [Open Letter to the Makers of Dark Winds, Jenny Kattlove](#)

"Behind the scars or misshapen features, the facially different are, of course, just like anyone else. We are most assuredly not evil. We long for warm inclusion, and to be welcomed for the “content of our characters,” as the great Dr. King once said. Your awareness can help."

Dr. Lise Deguire, burn survivor

Award Us

By Jaz Gray

Sometimes, they call us marvels
Simply because we have the audacity
to exist.

Oh, we get standing ovations.

Faces twisted, scarred, bulging.
People smile at us and say,
"Braaavo!"

Don't award us for breathing.

Award us for our acting jobs.
What perfect performances we have
learned to give.

Award us for pretending not to see
people pointing and hear the
whispers,
"What happened to her?"

Award us for how fast we can run!
Ducking, weaving, hurtling into
rickety bathroom stalls
Just to escape the stares.

Award us for how gracefully we grow
into adults who refuse the shame.

Who refuse to be silenced.

Who refuse to accept and expect less.

Who refuse to be on the sidelines.

While y'all have a field day
pretending it's a new day
In Hollywood.

Why the scary and the evil,
The helpless and the hooligan
Have to look like us?

While the pretty,
the famous,
They get to play at us.

They shine like trophies.
Yet each role is rotten
With our blood, our sweat, our tears.

What's masked as inclusion?
It's profit.
It's the bare minimum.

Outnumbered.
And yet you are outnumbered.
Millions now stand as one.

One day,
No one will marvel at why we look different.
They will wonder where we've been all this time.

Our stories
Our stages
Our stars

We belong.
These bodies
belong.

With our jagged faces,
missing limbs,
messy minds.

Those hired hands can never be us.
Those tired roles can never see us.
Change now or fools later.

History is watching in anticipation
At the edge of her seat
Like a nominated actor at the
Academy Awards.

“The media representation of disability centers a concern for the presence of disabled characters in mainstream entertainment narratives. Media participation demands particular attention to the lack of opportunities for disabled people to ultimately acquire equal access to resources needed to produce media independent of, and particularly within, the mainstream media industry. Such access can directly influence our capacity to overcome stigmatization and acquire the cultural, social, and material capital needed to become fully liberated.”

Extract from Redefining Disability, Jaz Gray, Professor and FD Activist

Changing the Narrative

Media representation has a powerful ability to promote acceptance for visible differences. By changing the way characters with visible differences are represented in the arts, creative professionals can have a real-world impact on the lives of individuals with visible differences.

Often due to inequity in the workplace and barriers to attaining influential roles in the arts, people with lived experiences are absent in the creative development process. This has a knock-on impact on the integrity of the stories we see on screens and stages, which can become tokenistic, and often not a reflection of the industry at large.



The Facial & Visible Difference Community asks media creators to:

1

Speak up and push back when you encounter damaging stereotypes about people with visible differences in the arts. Educate others about this issue and the consequences of negative portrayals.

2

Learn to recognize and avoid bias in your own work. When creating a character with a visible difference, pay for consultancy from real people with the relevant visible difference and avoid perpetuating negative and inaccurate stereotypes.

3

Include people with visible differences behind the scenes as creators, consultants, and participants in industry conversations and committees about diversity and inclusion. Ensure they are paid fairly for their services.

4

Cast real people with visible differences in leading and supporting roles, including roles where their visible difference is incidental and normalized. Avoid replicating visible differences with prosthetics.

5

Hire, remove barriers and make reasonable accommodations so that people with visible differences can be employed both in roles both behind the scenes, throughout the creative process, on screen or on the stage.

By taking these actions, you can shift the narrative about visible differences and facial difference in demonstrating your commitment to inclusive and authentic representation of all people with disabilities.

Recommended Reading

- [Guide to Writing Characters with Scars by Niki Averton](#)
- [Disfigured: On Fairytales, Disability and Making Space by Amanda Leduc](#)
- [Guidelines for Writing About People with Disabilities](#)
- [RespectAbility Guide to Inclusion in the Entertainment Industry](#)
- [CinemAbility: The Art of Inclusion](#)
- [The Ruderman White Paper on Authentic Representation in TV \(2018\)](#)
- [The case for authentic disability representation in media](#)
- [Facial Disfigurement on Screen](#)
- [International Media Standard on Disfigurement](#)
- [I am Not Your Villain \(Changing Faces\)](#)
- [Open Letter from Face Equality International on Lord of The Rings](#)

Thanks and Additional Info

Thanks goes to Niki Averton and the Phoenix Society for Burn Survivors for drawing upon her research for this paper (Averton, N (2020). Please Maim Responsibly: Crafting Scarred Characters in Speculative Young Adult Fiction. Vermont College of Fine Arts).

A full list of organisations within the FEI Alliance that have input into this paper can be found [here](#). Additional resources for businesses, media professionals, teachers, parents and beyond can be found in the [FEI Education Hub](#).

For additional information or consultancy inquiries, please contact us on info@faceequalityinternational.org



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