

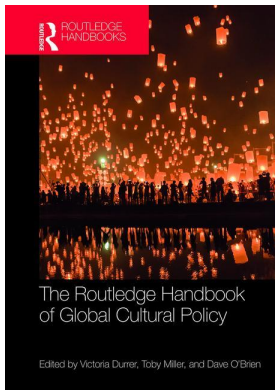
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Disabled people and culture

Creating inclusive global cultural policies

Anne-Marie Callus and Amy Camilleri-Zahra

Introduction

Cultural policy is inevitably shaped by dominant cultural assumptions. In many cultures, disability is largely viewed negatively, with disabled people seen either as tragic figures rendered bitter or helpless through their circumstances or as heroes bravely overcoming the odds created by their impairments. Such representations are oppressive for disabled people and continue to propagate a disabling culture. However, culture can be a source of liberation or emancipation (Brown 2003). In fact, the politicisation of disability has prompted a new disability culture, which challenges long-held stereotypes and traditional representations of disability. Through the disability arts movement, disabled people have sought to produce a culture aimed at exploring a positive identity of disability whilst combating the dominant disablist culture (Swain and French 2000, Arts Council England 2003). Disability culture can thus be an agent of change and a means of promoting and validating disabled people's own constructions of disability (Barnes and Mercer 2010).

Culture is a vast subject to deal with, has manifold manifestations and has developed in different ways around the world. In order to give this chapter a defined scope, we focus on five different cultural forms from a Western and mostly Anglophone cultural perspective, namely: narratives, poetry, visual arts, performing arts, and online media. The points raised are applicable to other forms of culture and to culture in different parts of the world. The relevance of the issues raised to cultural policy is highlighted throughout the chapter.

A note on terminology

In line with the social model of disability, as explained later in this chapter, a distinction is made between 'disability' and 'impairment'. Therefore, impairment is taken to mean 'the functional limitation within the individual caused by physical, mental or sensory impairment' (Disabled People's International 1982, p. 105), and disability to mean 'the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Disabled People's International 1982, p. 105). Thus, the term 'disabled people' will be used throughout this chapter in order to refer

to 'people with impairments who are disabled by socially constructed barriers' (Clark and Marsh 2003, p. 2) and to particularly emphasise the disabling barriers of stigma, prejudice and discrimination encountered by disabled people.

Disabled people's history: from rejects to rights holders

The year 2006 was a significant year for the disabled people's movement and for the one billion disabled people across the world. It was the year that the United Nations General Assembly adopted by general consensus the Convention on the Rights of Persons with Disabilities (CRPD). The adoption of the CRPD came after many years of relentless work by disabled people who were finally able to tackle discrimination and oppression through international legislation. One of the most significant aspects of the CRPD is that, for the first time, disabled people were directly involved in the drafting of a legislation that specifically targets them, in line with the disabled people's movement battle cry of 'Nothing about us, without us'. One of the eight general principles of the CRPD listed under Article 3 is: 'Full and effective participation and inclusion in society'. One way of ensuring the implementation of this particular principle is by securing the participation of disabled people in the arts and culture sector both as consumers and as producers. In addition, the right to participation in cultural life is also particularly enshrined in Article 30 of the CRPD, to which we return later.

In order to understand the need for enshrining disabled people's rights in international legislation, and the relevance of this legislation to cultural policy, it is important to be aware of the ways in which disability has historically been represented in culture. For its representation in Western culture, the focus of this chapter, it is interesting to note that the roots of the association between disability and weakness stem from the culture of ancient Greece. As Barnes (1996) points out, Greek city states were constantly warring with each other, and physical and mental prowess was therefore greatly valued. 'Inevitably in this type of society, physical and intellectual fitness was essential: there was little room for people with any form of flaw or imperfection', and severely deformed babies were left to die (Barnes 1996, p. 52).

The Judeo-Christian religious traditions are also considered to have exerted significant influence on cultural constructions of disability in Western Europe. Stiker (1999) explains, in his *History of Disability*, that in the Book of Leviticus (part of the Jewish Torah as well as of the Old Testament in the Christian Bible), disability is linked with uncleanness, although the duty to care for disabled people is emphasised. Stiker (1999) argues that these attitudes – of exclusion on the one hand and benevolence on the other – are not contradictory. 'Sin and defect deny the disabled a religious role, but they introduce an ethical and social imperative' (p. 27).

Therefore, bodily impairments have long been viewed as a sign of weakness, and responses have varied from ostracism to charity. Industrialisation and the concomitant need for people to be able to work new machinery and the imperative to be economically productive created a clear demarcation between disabled and non-disabled people (Barnes 1997). Advances in medicine and science eventually moved disability into the medical sphere, especially with the rise of rehabilitation after the First World War (Stiker 1999). In all of these cases, physical impairments place the disabled person outside the bounds of what is considered to be human normality. The same can be said for impairments, which affect the functions of the mind, such as mental health issues or cognitive impairments. These run counter to the value placed on rationality in Western philosophy, especially since the Enlightenment 'which put its faith in the power of human reason to explain the universe and provide a basis for morality' (Bowie 2003, p. 274). Foucault (2001) links the receding of the threat of leprosy at the end of the Middle Ages with the identification of the mentally disturbed person as the new scapegoat, the outcast.

The disabled person, whatever his or her impairment, has thus historically been placed outside of society not only physically but also conceptually. In his seminal critique of residential institutions for persons with intellectual disability in the United States, Wolfensberger (1972) links the setting up of these institutions with the deleterious cultural perceptions of the roles persons with intellectual disability are deemed to play within society. He identifies perceptions of the 'retarded person', the terminology used at his time of writing, as sick; a sub-human organism; a menace; an object of pity; a burden of charity; a holy innocent; a developing individual; and an object of merriment and ridicule.

A common feature of the different concepts and representations of disability outlined above is that they have all been conceived by non-disabled people. The perspectives of disabled people themselves would not gain any voice until the twentieth century, especially after the Second World War when the disabled people's movement became more vocal and effective. In the United Kingdom and the United States, people with physical disabilities were the first to campaign for their right to be included in a society adapted for their needs (Shapiro 1994, Campbell and Oliver 1996). Meanwhile, in these as well as Scandinavian countries, parents of disabled children placed in institutions were campaigning for the right of their children (most of whom had an intellectual disability) to live in community-based residences (Mansell and Ericsson 1995).

The most significant outcome of the disabled people's movement was convincing legislators and policy and decision makers of the need to shift responsibility for adapting and changing from the disabled individual onto society. This shift is linked to the acknowledgement that the difficulties encountered by disabled people are not simply the inevitable effect of their impairments, but also the effect of socially constructed barriers, which can often be removed. This led to the formulation of the 'social model' of disability by Oliver (1990). It is the model on which the distinction between impairment and disability, set out in the note on terminology above, is based. It is also the model on which the CRPD, various disability discrimination laws and policies are based.

The social model is therefore important for cultural policy. Guidance in this regard is provided by the CPRD (United Nations 2006), especially Article 30 Participation in cultural life, recreation, leisure and sport. Meeting the requirements of this Article entails ensuring that, first of all, disabled people have the means to express themselves through different cultural forms; second, they have access to cultural activities and cultural products and third, they enjoy recognition and support of their own cultural identities. The first two of these points are considered further below in this chapter. Addressing the third point entails first analysing the perspectives that dominate in the cultural representations of disability. The next section deals with the representations of disability in different Western, and especially Anglophone, cultural forms and relates the analyses to the development of disability-aware cultural policy.

Cultural representations of disabled people

There is a rich, and ever growing, body of scholarship that analyses historic and cultural representations of disabled people, some of which is explored in this section. The analysis provided in this scholarship shows that, generally speaking, the effect of normative and therefore exclusionary views of disability can be seen in traditional and even contemporary representations of disability in various cultural forms. These representations are increasingly counterbalanced by more nuanced representations of disability. The study of cultural representations of disability is vast. For reasons of space, this section considers just four types

of representations from high and popular culture: visual art, literature, film, and the use of disability in inspirational posters.

In his seminal work *Disability Aesthetics*, Siebers (2010) explores the role of disability in visual representations of the human body, especially in modern and contemporary art. Siebers states his position very clearly at the outset of his book:

My claim is that the acceptance of disability enriches and complicates notions of the aesthetic, while the rejection of disability limits definitions of artistic ideas and objects. (p. 3)

Siebers (2010) argues that, far from rejecting disability, art embraces it even if not always in an explicit manner. He uses the Nazi's stance on art as the prime example of how the pursuit of human perfection leads to sterility in art. Siebers refers to the Nazi's rejection of modern art as degenerate and sick. He contrasts Nazi sculpture, such as that displayed in the Great German Art Exhibition of 1939, with the *Venus de Milo*. The loss or 'amputation' of her arms does not in any way detract from her beauty. And while this 'amputation' was undoubtedly unintentioned by the original sculptor, it is highlighted in Magritte's 1931 version in *Les Menottes de cuivre* with its flesh-coloured body and the blood-like pigment on the stump of its left shoulder. As Siebers argues:

The figure of disability checks out of the asylum, the sick house, and the hospital to take up residence in the art gallery, the museum, and the public square. Disability is now and will be in the future an aesthetic value in itself.

(2010, p. 139)

Whether the disabled figure in modern and contemporary art is articulated as such is another matter. In her discussion of our perceptions of anomalous bodies, Silvers (2000) contrasts the attraction held by representations of such bodies in works of art and the rejection of these bodies in real life. She describes her own experience of wanting to keep looking at a Picasso portrait, with his trademark depiction of deformed faces, but avoiding to look at the face of her friend, who was born with facial and bodily deformities, and asks why this should be so. Silvers contends that:

we must conclude that ugliness is neither an objective property, nor is it an epiphenomenon of deformation or other objective anomalies, or else that ugliness pertains to being real, so that it is an objective property, but only of real things, and never of their artistic imitations or representations.

(2000, p. 203)

Therefore, while representations of disability in visual art are used as reflections on the human condition, culturally dominant interpretations of that art do not extend to reflections on what it means to live with a disability and on disabled people's culture.

Mitchell and Snyder (2000) make a related observation regarding literary representations of disability. Disabled people's physical and mental differences have been used extensively as literary devices, what the authors call 'narrative prosthesis'. One of the most famous prosthesis, in both the literal and the figurative senses of the word, is Captain Ahab's. His monomaniacal pursuit of Moby Dick, the whale that bit off his leg, is symbolised by his impairment in a way that, as Mitchell and Snyder (2000, p. 121) write, 'yokes disability to insanity, obsessive revenge, and the alterity of bodily variation'. Examples of the link between disability and negative emotions abound in literature. They are symptomatic of the fact that

disability is not seen as 'a natural part of the human condition. ... it was understood as an "attachment", as something extra that, for whatever reason, happened to a person' (Michalko 2003, p. 5). The inclusion of disabled characters in narratives therefore ironically serves to further entrench the exclusion of disabled people from society (Mitchell and Snyder 2000).

Another problematic aspect of this attitude towards disability in literature is that many depictions of disabled characters are not realistic. Susan Nussbaum, the disabled American playwright and novelist, writes thus:

I used to wonder where all the writers who have used disabled characters so liberally in their work were doing their research. When I became a wheelchair-user in the late seventies, all I knew about being disabled I learned from reading books and watching movies, and that scared the shit out of me. Tiny Tim was long-suffering and angelic and was cured at the end. Quasimodo was a monster who loved in vain and was killed at the end, but it was for the best. Lenny was a child who killed anything soft, and George had to shoot him. It was a mercy killing. Ahab was a bitter amputee and didn't care how many people died in his mad pursuit to avenge himself on a whale. Laura Wingfield had a limp, so no man would ever love her.

(2014, p. 301)

The works of literature in this quotation all have filmic versions, and the problematic depictions of disabled characters in them are transposed to the screen, as can be seen in Longmore's (2003) seminal review of some films where the main character has a disability. One of these is *Whose Life Is It Anyway?* (1981), which tells the story of Ken, a young sculptor who becomes quadriplegic following a traffic accident. Longmore (2003) criticises the film for distorting the contemporary situation with regards to the opportunities for rehabilitation and the assistive equipment that could have helped Ken lead a more independent life. For example, Ken is pushed around in a manual wheelchair instead of being given a power wheelchair that he could operate himself. But, as Longmore argues, introducing these elements would have undermined the validity of the claim that Ken's wanting to die was justified. 'If he operated a power chair himself, that would further undermine the false impression of his utter helplessness' (2003, p. 120). Significantly, a film that was released 23 years after *Whose Life Is It Anyway?*, *Million Dollar Baby* (2004), picks up on the same theme of a quadriplegic wanting to die – this time with the story of Frankie, a female boxer who is also paralysed from the neck down during a boxing match.

As a counterbalance to these narratives, others present more rounded portrayals of disabled persons. One such film is *My Left Foot* (1989), based on the autobiography of Christy Brown, an Irishman born with severe cerebral palsy who could only manipulate his left foot. In his review, Longmore (2003) comments that in this film Brown is portrayed as an agent in his own life who, although he does contemplate suicide at one point, has much to live for. This is also the case for two biopics, based on memoirs, of persons with severe physical disabilities – *Untouchable* (2011) and *The Theory of Everything* (2014). But, as Longmore argues, this is not necessarily how film critics see these characters. For example, he criticises a film reviewer who spoke of Brown in *My Left Foot* as helpless.

The point made by Longmore (2003) in this criticism touches on a very important issue regarding the reception of portrayals of disability by non-disabled people: seeing Brown as a helpless victim of his condition is a reflection of stereotyped misconceptions of what it is like to live with a severe and lifelong disabling condition. Such stances ignore the viewpoints of disabled persons, especially those of disabled activists, and remain entrenched in

the traditional equation of disability with tragedy and loss. This tendency can also be seen in the reactions to films portraying people with other types of impairments. One film whose reception by (presumably non-disabled) film reviewers and disabled activists provides sharp contrasts is *Tropic Thunder* (2008), a satire on Hollywood. Self-advocacy groups, led by people with intellectual disability, protested strongly against the film especially because of the repeated use of the word 'retard', which they find highly offensive, and the portrayal of the character Simple Jack (see for example Egle 2008). Jack (played by Ben Stiller) is presented as an ill-groomed, awkward and overgrown child and a grotesque embodiment of all the stereotypes associated with people with intellectual disability. Reviews of the film focus mostly on whether *Tropic Thunder's* satire, and Stiller's own brand of humour, work or not. Those reviewers who do refer to the issues raised by disabled activists tend to be dismissive of them.

Many scholars within the humanities and reviewers and critics whose job it is to appraise different cultural expressions do not seem to have caught up with the work of disabled activists and that of Disability Studies scholars. The negative connotations of disability that have been inherited from antiquity still appear dominant, albeit sometimes in subtle ways. For instance the portrayal of the disabled person as superhero is not, *prima facie*, a negative one. It is nonetheless problematic. Possibly one of the best analyses of what is wrong with such representations is by Stella Young (2014). Young criticises the portrayal of ordinary activities – such as working, studying and pursuing personal interests – as extraordinary simply because they are carried out by disabled people.

Young is particularly critical of what she calls 'inspirational porn' – the use of images of disabled people accompanied by inspirational quotes. One such image is a poster of the paralympian athlete Oscar Pistorius (prior to his shooting of Reeva Steenkamp) running on his blades alongside a small girl who also has prosthetic legs with a quotation from disabled figure skater, Scott Hamilton, 'the only disability in life is a bad attitude'. This and similar posters often shared on social media sites are problematic because they entrench the idea of disability as an individual problem, with the onus remaining on the disabled person to strive to overcome the challenges presented by the impairment rather than responsibility being placed on society to adapt itself to the needs of disabled persons. Such quotations can also lead disabled people to feel ashamed of their lack of achievement in different areas of life. And they can easily lead to a dehumanised view of disabled people. As Young (2014, at 2.33 minutes) states, in this view, 'We are not real people. We are there to inspire'.

The views of disability activists and scholars on the cultural representations of disabled people often remain the sole concern of those directly involved in the disability sector. However, the push for the inclusion of disabled people in the mainstream of society needs to be complemented with the mainstreaming of their culture and cultural identity, not least in cultural policy. Such a move entails taking on board the views of disability activists and scholars on the representation of disability in various forms of culture produced by non-disabled as well as by disabled people.

The cultural expressions of disabled people themselves merit analyses in their own right since they often run counter to the representations of disability found in mainstream culture. It is to these expressions that we must now turn.

Disabled people's own cultural expressions

In response to a negative disabling culture and with the aim of arguing against social exclusion and marginalisation, disabled people have been, especially since the 1980s, generating cultural expressions to create meaning from their own experiences of disability. They have

been using different forms of art to show the world that they are proud of who they are and that they claim their disability with pride as part of their identity (Brueggemann 2013). In fact, according to Swain and French (2000) and the Arts Council England (2003), one of the areas where a positive identity of disability is appreciably cultivated is definitely within the area of 'disability arts'. The philosophy of disability art is based on disabled people coming together and collectively identifying themselves as a group bound by experiences of oppression (Hargrave 2015). A focus on 'disability arts' is also made in Article 30 (2) of the CRPD, which highlights the need for State Parties to take all appropriate measures to give disabled people the opportunity to be producers of art themselves. In this section we shall be looking at some of disabled people's own expressions of culture within a Western and Anglophone context, namely theatre, poetry, art and music.

Britain saw the vigorous development of a disability arts culture in the mid-1980s. Disability arts culture is an integral product of the disability political movement of the 1970s and 1980s (Darke 2003). Disability cultural expression in Britain became mostly visible with the foundation of the London Disability Arts Forum, along with two influential magazines: *Disability Arts* and later *Disability Arts Magazine* (Darke 2003). The London Disability Arts Forum (LDAF) was founded in 1986 by a group of disabled artists and activists frustrated by the lack of provision for disabled people in the arts world and focused on promoting disability arts and the work of disabled artists (Darke 2003). LDAF used art as a means of identifying and revealing how cultural forms can have the power to establish a different world and not simply reflect an already given social world (Bowler 1994). LDAF aimed at putting forward cultural expressions that were inclusive, accessible, revolutionary and egalitarian in a social world that was exclusive and discriminatory towards disabled people (Darke 2003).

Similarly, the disability arts movement in America stemmed from disability activists who insisted on making their voices heard in all aspects of life through art and by affirming a positive identity of disability. Just as children of slavery came together to assert that: 'Black is beautiful', so, Owen (an American disability activist) claims that the disability arts culture in America is a product of disabled people coming together to mutually affirm a sense of pride and to express a desire to identify themselves with disability as a positive identity (Fleischer and Zames 2011). One of the areas where American disabled artists found space to express themselves was the magazine *The Disability Rag* (Nielson 2012).

Barnes and Mercer (2010) point out that disability arts have three aims: First, they are concerned with using the arts as a means of activism with the purpose of exposing discrimination and prejudice as well as challenging the stereotypes experienced by disabled people. Second, they are concerned with the exploration of the experience of living with an impairment and with giving positive value to disability. Third, through disability arts disabled people argue the case for mainstream access to artistic production and consumption.

Although through traditional paternalistic attitudes, art has often been regarded as an appropriate activity for special schools and day centres, or a form of individual therapy, 'disability arts' are politically influenced and take both a reflective and active orientation. Thus, as explained by Barnes and Mercer (2010, p. 207) there exists a very clear distinction between 'disability arts' and what they refer to as 'disabled people doing art'. 'Disability arts' is also different from the kind of art created by artists with impairments such as musicians Ray Charles and Def Leppard's drummer Rick Allen, who contrary to artists who produce 'disability arts', have reacted in a personal and private rather than in a political and overt way. The fundamental aim of disability arts is 'work of disabled artists, whose experiences with disability are recognised as an integral force underlying the artistic process' (Baglieri and Shapiro 2012, p. 100).

According to Vasey (1992), disability arts provides a space in which disabled people can come together to have a good time and also think about issues of common concern. One of the most popular expressions of art by disabled people for disabled people with the aim of ‘...speak[ing] the truth about the disability and experience’ (Masefield 2006, p. 22) and of bringing disabled people together is Johnny Crescendo’s song titled “Choices and Rights”. Johnny Crescendo is considered one of the first disability artists from the first wave of the Disability Arts Movement in the United Kingdom. His songs are considered extremely political, and he is well known for not being afraid of expressing his views directly (Sutherland 2008). The song with the words:

I don’t want your sorrow, I don’t want your fear, I want choices and rights in our lives,
I don’t need your guilt trip, I don’t want your tears, I want choices and rights in our lives
(www.disabilityartsonline.org.uk)

became known as the ‘anthem’ of the international disability rights movement (Campbell and Oliver 1996).

One of the aims of disability art is exposing negative images and stereotypes of disability as well as challenging the discrimination and oppression often encountered by disabled people (French and Swain 2012). One such cultural expression is Liz Crow’s film project titled *Resistance: Which way the future?* (2008). The project outlines the Aktion-T4 Nazi mass murder programme, which targeted disabled people. Liz Crow, through the main character named Ellie Blick, showed the atrocities that disabled people suffered as an effect of this mass murder programme. Furthermore, she drew a parallel between the Nazi’s oppression of disabled people during the Second World War and the discrimination that disabled people face today. Liz Crow later also accepted the request to participate in Anthony Gormley’s Fourth Plinth Project *One and Other* at Trafalgar Square in 2009 with the aim of giving more people the opportunity to engage with the act (Hambrook 2014). Liz portrayed her project by sitting in her wheelchair in full Nazi regalia whilst lifting a flag and quoting Niemoeller, ‘First they came for the sick, the so-called incurables and I did not speak out because I was not ill...’ (www.roaring-girl.com).

Bedding Out (2012) is another striking performance by Liz Crow. In an interview for *The Guardian*, Crow describes this project as ‘a sort of un-performance’ (Adewunmi 2013). *Bedding Out* is about making her private life public, something that according to Liz herself, she had not divulged for over 30 years. For a period of 48 hours, on stage, Crow performs the other side of her ‘fractured’ self, that is, her bed-life. In another interview in 2013, with the organisation Disabled People’s Against Cuts, Crow reveals how she wears a public self that is ‘energetic, dynamic and happening’ and has another, private, life she spends in bed due to her illness. According to Crow her private self is ‘...neither beautiful nor grown-up, it does not win friends or accolades and I conceal it carefully’ (Disabled People Against Cuts, 2012).

Canadian disabled scholar and activist Catherine Frazee explains that the role of disability arts in shaping disability cultures is vital. According to her (as cited in Johnston 2012, p. 10): ‘In Canada, the United States and around the world, [disabled] artists and performers...are contributing to one of the most radical and effective aspects of disability culture – challenging conventional notions of beauty, form and notion’. Riva Lehrer is a disabled artist who continuously challenges the conventional notions of beauty through her artwork. Lehrer actively campaigns for disability rights and disability pride through her art (Millett-Gallant 2010). Lehrer’s artwork offers a strong visual image of the human-nonhuman relationship between a disabled person and the environment.

In the painting “In the Yellow Woods”, Lehrer shows a woman kneeling on the ground in what looks like a forest, whilst peeling the bark off a tree branch with a knife. Surrounding the woman are human bones – a perfect pelvis, a rib cage and parts of the legs and spine, bones that look like they were carved from tree branches and tree trunks by the same woman. The bones look perfect and like they have not been marked by pain, surgery or breakage. The painting also shows the woman immensely concentrating on her task at hand, suggesting that these bones are a great necessity. Yet, the woman in the painting does not seem to be after creating wholeness or after a cure as has often been the role of narratives pertaining to disability (Anderson and O’Sullivan 2010). Rather, in this painting, the bones are scattered around her sinking into the ground and becoming part of the autumn landscape (Kafer 2013). According to Kafer (2013, p. 146), the painting is not about the triumph over disability, or an ‘ableist story of bodies without limitation’, but rather a story about a woman who is ‘...making a connection between caring for the body and caring for the earth’.

One particular characteristic of disability art is black humour, and this is clearly illustrated in one of the works of actor, playwright and poet Lynn Manning. His poem, “The Magic Wand”, about an African-American man with a white cane, cynically compares two stereotypes, one of racism and one of disability:

Quick-change artist extraordinaire,
I whip out my folded cane
and change from black man to blind man

Manning is well known for his autobiographical solo *Weights*. The play is about Manning’s own personal journey of being a black man who, at the age of 27, also became a blind man after having been shot by a drunk driver (Piggott-McMillan 2005). Through *Weights*, Manning brings to the forefront a chronology of experiences from his childhood to his life after the shooting with a touch of funny episodes about his adjustment to blindness. *Weights* premiered in 2000 and went on to receive a Fringe Review Theatre Award at the 2008 Edinburgh Fringe Festival (www.lynnmanning.com).

As mentioned in the first section of this chapter, for many years, the definition of disability has been rooted in a medicalised understanding (Barnes 1997). According to Oliver (1990) the representation of disability as a pathology reduces its experience to a tragedy borne only by the individual and treatable only through the intervention of health. Furthermore, Oliver (1990) contends that the medicalisation of disability often affects the individual experience of disability. Disability art has been used as a powerful tool to question the medicalisation of disability and to challenge ableist assumptions (Darke 2004). Neil Marcus, a New York poet and playwright, uses his poem, “Disabled Country” to claim disability as an identity and to move out of the shadow of constant medicalisation:

If there was a country called disabled,
I would be from there.
...I came there at age 8. I tried to leave.
Was encouraged by doctors to leave.

In addition, Marcus uses the poem to explain how through his life he has had to take on a project, that of making himself comfortable and “at home” in his country called “disabled”, a process both personal and political (Hall 2015).

The final example of disability art brings to the fore the role of the non-disabled artist in disability arts. The statue of *Alison Lapper Pregnant*, referred to by many as a collaboration between Quinn and Lapper, received contrasting comments during its participation in the Fourth Plinth Project in London's Trafalgar Square (Millett 2008). Alison Lapper, a contemporary artist and photographer born without hands and feet, posed naked whilst pregnant for the sculptor Marc Quinn, who in Lapper's own words managed to capture her as "naked, pregnant and proud" (as cited in Smith 2015). Quinn wanted to draw attention to stereotypes and to include them in public debate with the aim of educating the public (Millett-Gallant 2010). As Millett (2008) points out, *Alison Lapper Pregnant* makes a public statement about this disabled woman's right to be represented as a productive social subject and a reproductive sexual being and her right to represent others. The statue of Alison Lapper brings to the foreground two intertwining identities, that of a disabled identity and that of a gendered identity (Garland-Thomson 2010).

Notwithstanding the considerable amount of disability art created by disabled people with the aim of putting forward a positive identity of disability and the adoption of the CRPD by the United Nations, particularly Article 30 (2), most disabled people still encounter obstacles when trying to access mainstream culture both as producers and as consumers. Access to culture will be discussed in the next section.

Access to culture

We have so far explored how, on the whole, various forms of culture produced by non-disabled people do not acknowledge disabled people's cultural identities and how performances, writing and cultural expressions produced by disabled people run counter to dominant cultural representations of disability. As seen above, Article 30 of the CRPD (United Nations 2006) affirms the right of disabled people to these cultural expressions and to accessibility in the sphere of culture. It sets out arrangements that need to be in place for this right to be enjoyed. While it is important that on a conceptual level disabled people's own cultural expressions and their critique of mainstream representations of disability inform cultural policy, it is also essential for cultural policy makers to be aware of how to make these expressions and representations accessible to all.

One of the obligations included in Article 30 concerns the provision of 'access to cultural material in accessible formats', including by ensuring that 'laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials' (United Nations 2006, p. 22). The reference point in this regard is the Marrakesh Treaty, adopted by the World Intellectual Property Organisation (2013). This Treaty covers the rights of persons who have difficulty accessing printed material, such as those with visual impairments, those who have other reading difficulties and those who cannot physically handle a book or move their eyes to be able to read. Countries ratifying this Treaty are obliged to ensure that intellectual copyright laws do not hinder persons with print disabilities from accessing printed material such as novels, poetry anthologies and scripts, in accessible formats, such as Braille, large print and electronic and audio formats. The latter two have become increasingly possible thanks to advances in information and communication technology.

Another aspect of access to information is the Internet, including social media. The World Wide Web Consortium (2015) provides guidelines for ensuring access to websites and web-based services. Yet another aspect is access to information for people with intellectual disability. Generally speaking, this requires the provision of easy-to-read material – both in terms of creating documents that are easy to read and providing easy-to-read versions of

already existing documents such as the ones mentioned above. The Department of Health's (2010) guidelines as well as those published by Mencap (no date) are very useful in this regard.

Access, as set out in Article 30 of the CRPD, is also related to accessibility to audiovisual material, including sign language interpreting for deaf persons, captioning for hearing-impaired persons and audio description for visually impaired persons. Sign language interpreting is also possible for plays, musicals, dance and other performances. The usual practice is for specific performances to provide this service. Article 30 also specifies access to, among others, 'theatres, museums, cinemas, libraries and tourism services, and, as far as possible, ... access to monuments and sites of national cultural importance' (United Nations 2006, p. 22). The Centre for Universal Design (2015) provides comprehensive guidelines regarding access to the built environment, outdoor environments and products. Museums offer a good example of how different aspects of accessibility can be brought together (Chimirri-Russell 2010, Sandell and Dodd 2010). The most obvious aspect is physical access to the museum and to the rooms and facilities within it. Then there is also access to information – including sub-titling of audiovisual information, Braille of printed information and the provision of easy-to-read information sheets. Because museums are largely based on providing visual information through their various exhibits, they should also offer additional arrangements for people with visual impairments. These include audio descriptions, touch tours that are provided at set times and tactile zones where visitors are allowed to touch certain artefacts (for example reproductions of sculptures or scale models of buildings); for more on this topic see Strechay and Annis (2012).

Crucially, Article 30 also deals with disabled people's right 'to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society' (United Nations 2006, p. 22). This includes having access to 'appropriate instruction, training and resources' (p. 23). It also means, of course, giving disability arts their due importance and providing the spaces and resources for them to flourish.

Conclusion

In conclusion, it is vital for the makers of cultural policies, and those involved in their implementation, to take disabled people's issues into account. As seen in this chapter, they need to understand historical and contemporary influences on cultural representations of disabled people, especially through the insights afforded by Disability Studies scholars. They also need to appreciate the unique contribution made by disabled people to culture especially through disability arts, in which the experience of living with a disability is foregrounded in an affirmative manner. Finally, cultural policy makers and implementers need to recognise how they can and should set about ensuring disabled people's access to culture as consumers and producers of culture themselves. These three points are intimately linked, and by taking them into account we can help ensure that cultural policy and its implementation truly represent the variety of human experience and the meanings made out of that experience.

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