

‘Effecting Change; Disability, Culture and Art’?

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Introduction

During the latter half of the twentieth century, disabled people across the world began to express themselves in a variety of cultural forms including painting, sculpture, literature, poetry, music, theatre and dance. This is not necessarily a new phenomenon however. People with accredited impairments have been involved in cultural production - the arts and sciences - since the ancient world of Greece and Rome.

Indeed, for centuries impairment and suffering have been seen as an almost necessary prerequisite for creativity and artistic endeavour. What is significant about recent developments within the context of disability art is that since the emergence of the international disabled people's movement in the 1970s, disability art has become inextricably linked to a radical new 'disability politics and culture'; its aim is to bring about a more equitable and inclusive future.

In this presentation I will begin by exploring the relationship between culture, politics and art. I will then provide a brief overview of the emergence of the disability arts movement, and finally I will critically evaluate some of the important implications of disability art and a disability culture.

Culture, politics and Art

It's important to note at the outset that 'culture' is a particularly elusive concept that means many things to many people. In the broadest sense, for example, it is inevitably linked, in one way or another, to politics and is often used to refer to an overarching set of values and norms associated with a particular group, community, nation or society. Hence, parliamentary democracy, freedom of choice and the 'English' language are generally associated with western culture.

But, historically, the word 'culture' has also been used with reference to 'the best that has been thought and said' in a particular society and age'. Here 'culture' encompasses the sum of the 'great ideas' to be found in the classic works of literature, painting, sculpture, music and philosophy. Highly prized and appreciated by often only a relative minority, such works are frequently referred to as 'high culture' (Hall, 1997).

More recently, but within the same train of thought, the term has been used with reference to the more widely distributed artefacts of everyday life. Examples include television programmes, pop music, pulp fiction, art design, fashion, leisure activities and lifestyle. This is referred to as 'mass' or 'popular culture'.

High culture versus popular culture was, for many years, the classic way of framing debates about culture, with both terms carrying a value judgement - 'high' culture being good, and popular culture being for 'mass' consumption and thus somehow debased or bad (Hall, 1997).

It is worth mentioning that discussions about the relationship between mainstream or 'hegemonic' culture and minority or 'subcultures' are also significant. Dominant cultures are often perceived as oppressive by some sections of society. Consequence oppressed groups sometimes develop their own cultural norms and values. These then provide members with an individual and collective defence mechanism against oppression, as well as a form of cultural resistance. Well known examples include Afro Caribbean Rastafarian culture, and Gay and Lesbian cultures.

Besides contributing to mainstream pop culture in terms of music and fashion, these subcultures also constitute an alternative lifestyle. In many ways therefore, these and other sub-cultural forms are important mechanisms for generating social change in the sense that they represent a growing and general dissatisfaction with dominant cultural values.

From this perspective, therefore, subcultures constitute a kind of 'counter hegemony' with the potential for challenging and, in the long term, changing mainstream culture. All of which has relevance to the debates about disability culture and art. Indeed, as many disabled activists and scholars have pointed out western culture is replete with negative images of disabled people. It is therefore a predominantly non-disabled culture - its norms and values are those of non-disabled people.

Disability culture, on the other hand, is therefore a minority, sub, or subordinate culture. It emerged from within, and is associated with, the international disabled people's movement, and reflects the norms and values of disabled activists, their supporters and allies. Key elements of disability culture are the redefinition of disability by disabled people and their organisations, and the radical socio/political interpretation of disability commonly referred to as 'the social model of disability'.

The radical socio/political interpretation of disability entered the political arena in 1974 following the groundswell of political activity amongst disabled people across the world during the previous decade. The critique of 'able-bodied' society and orthodox individual medical interpretations of disability was first codified into a radical alternative by Britain's Union of the Physically Impaired Against Segregation (UPIAS). Comprised exclusively of people with physical and sensory impairments, the UPIAS manifesto entitled *The Fundamental Principles of Disability* (1976) contains the profound assertion that it is society that disables people with impairments.

In our view it is society which disables physically impaired people. **Disability** (emphasis added) is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS 1976: 14).

The UPIAS' analysis of the disabling society is built on a clear distinction between the biological (impairment) and the social

(disability), and is contained in their Policy Statement of 1974. Here Impairment denotes 'Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body' and disability is:

'The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS 1976: 3-4) .

Clearly, the medical conceptualisation of physical impairment has been retained, in contrast to the definition of disability in socio-political terms.

Such an approach renders the use of the phrase 'people with disabilities' problematic since it blurs the crucial conceptual and analytical distinction between the biological and the social. This has caused considerable confusion outside the United Kingdom since many non-English speaking countries have no equivalent, or are unhappy, with the term impairment. The confusion is further compounded by the tendency amongst academics and professionals to ignore the theoretical and investigative implications of the UPIAS construct.

Nonetheless, the UPIAS approach was later adopted and adapted by many organisations controlled and run by disabled people including, in 1981, the British Council of Organisations of Disabled People (BCODP) and Disabled People's International (DPI), to encompass all forms of impairment whether physical, sensory or cognitive (Barnes, 1991: Driedger, 989). The BCODP is Britain's national umbrella for organisations controlled and run by disabled people and DPI is the international equivalent for national agencies such as the BCODP.

This holistic approach is based on the insight that in a society geared almost exclusively to the needs of mythical non-disabled ideal, physical, sensory and cognitive impairments are inevitably interrelated. Also labels have little meaning beyond the need for

appropriate medical treatments and social supports; they are also socially and politically divisive.

Moreover, this re-interpretation of disability has facilitated the construction of a 'social model' (Oliver, 1983) or 'social barriers model' of disability (Finkelstein, 1991). This approach focuses on the various barriers: economic, political and cultural, encountered by people with accredited impairments. Thus 'disability' is not a product of individual failings but is socially created; explanations for its changing character are found in the organization and structures of society.

Disability culture may be differentiated from mainstream culture in other ways too. First, interacting with other disabled people is often especially important for people with accredited impairments, because in the majority of cases disabled people are unable to share the same experiences as non-disabled people or conform to mainstream norms and values. Second, within the context of disability culture there is an acceptance of impairment as a symbol of difference rather than shame, and recognition of the significance and value of a disabled lifestyle.

This can mean anything from articulating the experiences of impairment and disability openly and without shame, through to the rejection of prostheses or other artificial aids designed to conceal or minimise the visibility or effects of impairment. Thus the 'cause of the problem' is inverted to become a source of individual and collective empowerment and pride.

Finally, since the 1970s, disquiet over the prevalence of disablist imagery in popular culture and the arts among the disabled community has prompted the development of a positive alternative, now known as the disability arts movement.

Consequently, disability politics and disability arts are intimately connected. For the disabled activist and writer Alan Sutherland:

disability arts would not have been possible without disability politics coming along first. It's what makes a disability artist

different from an artist with a *disability*. (emphasis added)
(Sutherland, 1997: 159)

This is important because the relationship between impairment, culture and art is intertwined and extremely complex.

Indeed, throughout recorded history impairment and 'suffering' have been viewed as an almost necessary prerequisite of creativity and artistic endeavour. There are many examples of famous writers, poets, artists and musicians with long term illnesses or accredited impairments.

For examples, although his existence is open to conjecture, Homer, the Greek philosopher and poet, is but one important example. Other well known examples include Ludvic van Beethoven (1770 - 1827), Lord Byron (1788-1824), Vincent Van Gogh (1853-90) and Henri de Toulouse Lautrec (1864-1901).

The stereotype of the 'flawed' artist remains as strong as ever within western culture. Post-punk singer Ian Curtis, of the cult rock band *Joy Division*, for example, owed some of his reputation for tragic extremism to his epilepsy. But while impairment may on occasion be said to add to the appeal or the insight of a particular artistic figure, it is important to remember that many artists with accredited impairments have denied or ignored this aspect of their lives.

Others have reacted in a personal rather than a political way. Contemporary examples include musicians Ray Charles, Jacqueline du Pré, Evelyn Glennie, Stevie Wonder, Hank Williams and Ian Dury. However, the connection between biology and art represents a complete contrast with art as therapy or disability arts.

Traditional responses to the issue of disabled people and the arts have been based on paternalism. Those disabled people viewed as inadequate and incapable have been given art as therapy in the context of special schools, day centres, and segregated institutions. Such initiatives have not just individualised and

depoliticised creativity, advocates have also sometimes used them for commercial purposes, such as charity Christmas cards.

Whilst there is arguably a place for art therapy, disabled people do not deserve this presumption of perpetual infantilisation, and increasingly, have refused to put up with it. For Allan Sutherland:

The term 'art therapy' is one of those phrases, like 'military intelligence', that contains an internal contradiction. Art therapy uses the forms of art for entirely unartistic ends. In particular it leaves out communication, for it assumes we (disabled people) have nothing to communicate.
(Sutherland, 1997: 159)

Disability arts, on the other hand, is all about communication. In particular, it stresses the role of the arts in developing cultural (and by inference political) identity:

Disability arts... provides a context in which disabled people can get together, enjoy themselves and think in some way about issues of common concern. But it goes deeper than that, as disability culture really does offer people a key to the basic process of identifying as a disabled person, because culture and identity are closely linked concepts. (Vasey, 1992: 11)

Disability art is, therefore, about exposing the disabling imagery and processes of society. There is also a role to play alongside conventional political activities:

Arts practice should also be viewed as much as a tool for change as attending meetings about orange badge provision ... Only by ensuring an integrated role for disability arts and culture in the struggle can we develop the vision to challenge narrow thinking, elitism and dependency on others for our emancipation. To encourage the growth of a disability culture is no less than to begin the radical task of transforming ourselves from passive and dependent beings

into active and creative agents for social change. (Morrison and Finkelstein, 1992: 11-12)

Thus, disability art is potentially educative, transformative, expressive, emotionally exploratory, participative, and involving. It is a conception of cultural action that owes much to playwrights such as Berthold Brecht and educationalists like Paulo Freire because it is radical, challenging and progressive at an individual and social level. Brecht was a well-known German Marxist dramatist whose plays and songs focus on oppression and injustice, and Freire, a Brazilian teacher and writer, perceived education as an important means of transforming people's political consciousness.

It is a sign of the maturity and confidence of the disabled people's movement that disabled people are able to celebrate difference, and work together to create and discuss images of their own choosing. Mainstream arts have not confronted disability. Moreover, disabled people are often dis-empowered, if not excluded, by arts training. Therefore, developing their own art, in environments controlled by themselves, is seen as critical if disabled people are to develop as creative producers, and compete with artists in the mainstream.

It is for this reason that the disabled people's movement has supported and nurtured its own artists and sought to provide for them opportunities to experiment and develop the necessary experience and confidence (Cribb, 1993). Hitherto, the difficulty has been to avoid imposing a non-disabled view of quality. It is vital to recognise the process on which people are engaged, the struggle against barriers involved in getting there, and the context in which work is presented (Pick, 1992).

There is little doubt that there has been a lack of a positive cultural identity for disabled people to draw upon, and in the face of extensive cultural oppression disability culture and art has had to be created almost from scratch.

The origins of disability culture and art

There is little doubt that disability culture and art is a product of the late twentieth century, and that the process of exclusion has played a significant role in its development. It is highly likely however that disabled people throughout recorded history - in various circumstances and to varying degrees - have developed alternative value systems based around their own values and unmet needs rather than those of the dominant majority.

Certainly, ever since the ancient world of Greece and Rome disparate sections of the disabled population have found themselves thrown together whether through choice or otherwise. Indeed, in eighteenth century Europe the practice of segregating the most 'severely impaired' members of the community into institutions of various kinds was gradually extended to include other sections of the population. In the UK it was a practice that continued well into the 1960s and 70s.

Given the tendency among all other marginalised or 'outsider' groups to develop alternate value systems it is almost inconceivable that those excluded on the basis of perceived impairment would not have done the same.

This process of exclusion generates a shared experience for inmates. Examples include the experience of separate schooling, segregated transport, dealing with professionals, welfare services, rehabilitation agencies and charities. Many people born with congenital impairments will experience the same institutionalised educational experiences, just as people who acquire impairments will often share the same medical experiences.

To this extent it is possible to talk of a shared culture, albeit one based on the experience of oppressive institutional settings. Certainly the seeds of a proactive disability culture are clearly visible in the early writings of Paul Hunt, himself an inmate of various residential institutions for most of his adult life:

I would suggest that our role in society can be likened to that of the satirist in some respects. Maybe we have to remind people of a side of life they would sooner forget. We do this primarily by what we are. But we can intensify it and make it more productive if we are fully conscious of the tragedy of our situation, yet show by our lives that we believe this is not the final tragedy. (Hunt, 1966: 156)

The process of exclusion was fundamental to the development of Deaf culture. For the American writer Lennard Davis, Deaf culture has its roots in the eighteenth century, with the discovery of 'deafness' and the development of schools for deaf children.

Of course many authors had written about deafness before then. But for Davis the emergence of these schools signals a major qualitative change in deaf people's individual and collective experiences. Hitherto, they had had no shared experience. On the whole they remained isolated from each other and were therefore, without a shared, complex, language (Davis, 1995).

However, in understanding the cultural experience of deafness, it is necessary to distinguish between people with hearing impairments, who have often acquired or developed hearing loss, are not native users of British Sign Language (BSL), and may be described as deaf, or hard of hearing; and those with congenital hearing impairment who have grown up in a BSL environment, perhaps due to having Deaf parents, and therefore define themselves as Deaf.

Many Deaf people explicitly refer to themselves as a cultural or linguistic minority, making the analogy with minority ethnic groups, who are similarly likely to be excluded because English is not their first language. At the same time, they resist identification as 'disabled people' or people with impairments. This political approach has sometimes proved a stumbling block to relations between Deaf people and the disabled people's movement as a whole (Corker, 1998).

A further element in the development of disability culture and the arts that should not be over-looked is the relationship between disabled people and the 'entertainment' industry. Historically, people with perceived impairments or 'abnormalities' have provided an important source of entertainment for the non-disabled majority.

The ancient Egyptians, for example, used blind people as musicians, artists and masseuses. 'Deformed slaves' were highly prized among the Greeks and Romans. The custom of keeping such slaves as entertainers became popular during the Hellenistic era. People of short stature or 'dwarfs' were particularly popular in Athens and Imperial Rome (Garland, 1995).

Throughout the medieval period, society's apparent 'fascination' with perceived abnormalities persisted. Many royal courts in Europe between 1600 and 1800 retained people of short stature as 'court jesters' or kept a compliment of 'fools' (these were people with learning difficulties or others who feigned 'idiocy' for amusement). During the Middle Ages and thereafter, people with perceived 'deformities' and intellectual impairments were often displayed for money at village fairs and on market days, festivals and holidays.

Such practices became institutionalised in the nineteenth century with the development of the 'freak show', a phrase used to refer to 'the formally organised exhibition of people with alleged physical, mental or behavioural difference at circuses, fairs carnivals or other amusement venues' (Bogdan, 1996: 25). 'Freak shows' flourished throughout Britain and North America in the nineteenth and early part of the twentieth century.

Although these exhibitions were undoubtedly frequently the site for the uncontrolled exploitation and degradation of people with impairments, for some they provided a welcome refuge from the pathologising gaze and controlling influence of the newly ascendant medical profession. Many viewed themselves as professional performers and an essential part of show business (Bogdan, 1996).

Due in part to the economic, political and social changes of the 1940s and beyond, the popularity of the freak show has declined markedly. Moreover, since the politicisation of disability in the 1960s and 70s disabled people's involvement in the performing arts has changed considerably.

The Disability Arts Movement

Clearly then the Disability Arts Movement is not simply about disabled people obtaining access to the mainstream of artistic consumption and production. Nor is it about simply expressing the individual experiences of living with or coming to terms with an accredited impairment.

Disability art is the development of shared cultural meanings and collective expression of the experience of disability and struggle. It entails using art to expose the discrimination and prejudice disabled people face, and to generate group consciousness and solidarity. For a growing number of people around the world, the main forum for positive cultural representations of the disability experience is only located within the context of Disability Arts.

Early initiatives in the disability arts movement include the production of *Link*, a television programme specifically for disabled people, by a British independent production company; and the production of newsletters and magazines by the disabled people's movement.

Examples include *The Disability Rag*, the unofficial newspaper of the American Independent Living Movement started in 1980; *In From the Cold*, the magazine produced by Britain's Liberation Network of Disabled People, established in 1981 - the last edition appeared in 1987; *Coalition*, the magazine of the Greater Manchester Coalition of Disabled People (GMCDP) - it first appeared in 1986 and is still going strong and; the *DAIL* (Disability Arts in London) Magazine. Whilst all these periodicals include articles, features, reviews, and commentary on disability

issues, culture and art, the latter, as its name implies is devoted exclusively to arts practice.

DAIL began operations in 1987, it has a national circulation of 3000, and an estimated 8000 readers (*DAIL*, 1999). Further illustrations of this trend include the setting up of *London Disability Arts Forum* in 1986, and a general upsurge in conferences, exhibitions, workshops, cabaret and performance throughout Britain. All of which has generated a wealth of artefacts including paintings, sculpture, novels, poetry, plays, music and performance art both in Britain and the rest of the world. Indeed, recent research by the newly formed Edward Lear Foundation shows that there are currently over 50 organisations and agencies involved in the development of Disability Art in the UK alone (Edward Lear Foundation, 2003).

Also, there is an increasingly 'politically aware' disability voice reflected on film and in other media produced by disabled people. It represents a growing body of work that takes:

legitimate and conscious account of the film maker or artist's encounter with and progress through the experience of disability. (Pointon, 1997: 237)

Well known early examples include Steve Dworskin's *Trying to Kiss the Moon* (UK) and Billy Golfus's *When Billy Broke his Head and Other Tales of Wonder* (USA) (for a comparative review see Darke, 1995).

Moreover, the London Disability Arts Forum is to stage its 5th Disability Film Festival at the National Film Theatre from the 5th to the 8th of June. The festival includes presentations and 60 films from all over the world (www.disabilityfilmfestival.net). It was also recently reported that there was exceptionally fierce competition for recognition at this year's annual International Disability Media Festival 'Superfest' organised by the American 'Corporation on Disabilities and Telecommunication' (CDT) with a similar number of entries from 'Canada, Israel, Europe and throughout the US. Subjects covered in these films included taking a fresh look at:

'freakshows, satirizing how Helen Keller might have learned to communicate, getting beneath the surface glitter and clichés of wheelchair sports, capturing the brutal essence of past and present discrimination, or challenging researchers to work more closely with disabled persons' (Disability World, 2003).

All of which tends to contradict the Canadian writer Susan Wendell's (1996: 273) assertion that:

It would be hard to claim that disabled people as a whole have an alternative culture or even the seeds of one.

Furthermore, in recent years film makers in Hollywood and elsewhere have produced panoply of films that arguably reflect different aspects of the 'disability' experience. There are also more 'disabled' characters (although not all are played by actors with impairments) in British soaps and dramas (Pointon, 1997). Whilst these developments might not go far enough for some disabled activists, there can be little doubt that there is a much greater range of 'mainstream' material dealing with disability issues available.

It may also be argued that the impact of disability culture and art is having quite tangible effects within the context of mainstream culture. In the USA for example, *The Americans with Disabilities Act* (ADA) forced suppliers of television sets to build in a decoder chip so Deaf people could receive 'closed caption' (a type of subtitling system for viewers with hearing impairments).

In the UK, £50,000 of National Lottery funding has awarded to Derby's *Royal School for the Deaf*, to help build Europe's sign language video library. This is the first phase of the establishment of a £1 million National Sign Language Video Centre. There has also been a consistent growth in the number of signed theatre performances for deaf people (Pointon, 1997).

There has also been a general expansion in the number of 'positive' images of disabled people. Indeed, in the mid 1980s Paul Longmore (1987) commented on these developments in American advertising with disabled characters appearing in advertisements for Levi Jeans, McDonalds Hamburgers, and Kodak films - a trend which has yet to cross the Atlantic.

Nonetheless, the emergence of disability culture and its relative success raise a number of important issues that are not easily resolved. Notions such as 'disability pride' and the 'celebration of difference' are for many people quite problematic. This is particularly the case with reference to those whose impairments are debilitating, painful, or likely to result in premature death. Whilst other oppressed groups may proclaim that 'black is beautiful' or pronounce themselves 'glad to be gay', it is harder for many disabled people to make similar claims.

While agreeing that the main determinants of disabled people's quality of life are social, not medical, many would contest the optimism of Jenny Morris' suggestion that:

We can celebrate, and take pride in, our physical and intellectual differences, asserting the value of our lives.
(Morris, 1991: 189)

It may be necessary to develop an attitude of ambivalence towards impairment: on the one hand, asserting the value of people with perceived impairment/s, and on the other hand, refusing to glorify incapacity. Central to this process is the distinction between impairment and disability. It is possible to celebrate the resistance and strength that the collective movements of disabled people have demonstrated throughout the world in the last few decades, and to take pride in the survival and self-organisation of disabled people and their organisations.

Moreover, the development and very existence of disability culture and art may itself be exclusionary, and in turn, compound the difficulties experienced by disabled people as it can very easily alienate potential non-disabled allies. By definition disability

culture and art are the outcome of a 'minority group' consciousness. As a consequence, their potential for initiating meaningful and radical political and social change may be limited. Moreover, the disability arts movement has yet to make a significant impact on other sub-cultural groupings. Finally, as various aspects of disability culture and art are assimilated into mainstream culture their political significance may be effectively neutralised.

Conclusion

The last decades of the twentieth century have witnessed the emergence of a burgeoning disability culture and arts movement. Undoubtedly a new phenomenon, disability culture can be likened to other sub-cultural forms. Additionally, its roots are long and varied and lie in the complex relationship between perceived impairment and the creative arts. Whilst there is little doubt that the disability arts movement poses a significant challenge to conventional assumptions about impairment and disability, its very existence and relative success raise a number of important questions that have yet to be fully resolved. But how and in what ways these questions are to be addressed can only be decided by disabled people themselves.

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Disability culture has always existed. Whenever two or more disabled people compare notes about their experiences, anytime a disabled person writes about their thoughts and feelings, wherever disabled people have shared the products of their creativity there is Disability Culture. But online media have vastly expanded and diversified Disability Culture, lowered barriers to participation, and made it more easily available to disabled people and others. Disability Culture is still relatively unknown to most people, including many, maybe even most, people with disabilities.Â But the unique accessibility and penetration of digital media is changing that very quickly. The following are suggested entry points for anyone who wants to explore and participate in Disability Culture online. Disability politics and the disability arts movement,are now inextricably linked and a world wide phenomenon.,This paper explores the links between disability politics, culture and art, provides a broad overview of the disability arts movement, and critically evaluates,the implications of these phenomena,for both disabled and non disabled people and the struggle for a more inclusive society.Â Because traditional responses to disabled people and the arts have been based upon the medical model of disability the experiences of disabled in the arts took on a paternalistic approach. Much in the same way that the medical model in its paradigm of