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Abstract

In this article the author demonstrates that contemporary cultural disability discourses offer few positive resources for people with impairments to draw upon in constructing positive personal and social identities. Examining the emergence of the Disability Arts Movement in Britain, consideration is given to alternative discourses developed by disabled people who have resisted the passive roles expected of them and developed a disability identity rooted in notions of power, respect and control. It is suggested that these alternative discourses provide an empowering rather than a disabling basis for community development and community arts practice and should be embraced by workers in these fields.

Oppressive Images

So often do they hear that they are good-for-nothing, know nothing and are incapable of learning anything – that they are sick, lazy and unproductive – that in the end they become convinced of their own unfitness (Friere, 1996:45).

Friere's words may have referred originally to the situation of Brazilian peasants in the 1960s, but they have a universal quality and may legitimately be applied to the experience of disabled people in Britain in the first decade of the 21st Century. When the discourses of dominant culture present disability in terms of personal tragedy, dependence, and incapacity, it is to be expected that many disabled people come either to accept poverty, unemployment, restricted life chances and social exclusion as the consequences of their own individual characteristics as not-quite-good-enough human beings (Oliver, M. 1996); or to distance themselves from the term, avoiding contact with other disabled people for fear of being discredited through association (Titchkosky, 2006:224). I use the term 'culture' here to refer to everyday social practice and interaction as well as to the arts. It is the practice through which people make sense of themselves as actors in their own cultural worlds (Willis, 2000).

Mainstream cultural texts, past and present, provide a negative and narrow range of stereotypes and representations upon which people with impairments can draw in order to make sense of their own being-in-the-world and from which to construct personal and social identities. Disabled people are overwhelmingly represented as either pitiable and pathetic; sinister and evil; or tragic but brave (Rieser and Mason 1992:98). Rosemary Thomson (1997) has drawn attention to the fact that within fictional literature disabled characters are usually one-dimensional and passive. Paul Darke (1998:184) has identified the existence of a 'normality genre' in film, in which disabled characters fulfil the same function as 'Red Indians' in westerns or aliens in sci-fi movies: representing a threat to the fabric of normal decency which has to be resolved (usually in the case of normality films through the disabled character being either killed or cured) in order that normality can be preserved or restored.

This oppressive representation reflects values and assumptions in a cultural context in which disability is conceptualised through what is known as the medical model. The medical model of disability is most clearly identified in the World Health Organisation's International Classification of Impairments, Disabilities and Handicaps. Impairment here is defined as 'any loss or abnormality of psychological, physiological or anatomical structure or function'; while disability is recognised as 'any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range

considered normal for a human being' (Barnes, Mercer, and Shakespeare, 1999:23). In other words, disability is regarded as an individual problem, emerging as a result of something 'wrong' with the bodies of people with impairments, to be responded to by making normalising, compensatory, or therapeutic interventions in the lives of people with impairments.

In terms of industrialised capitalism this way of thinking about and representing disability has a fairly lengthy history but shows little sign of disappearing. It is easy to find these stereotypes in Victorian classics where we would expect to find them. There is the poor, pathetic victim, Tiny Tim in Dickens' 'A Christmas Carol' (2003); the bitter and twisted monster, Blind Pew in Stevenson's 'Treasure Island' (1998); and the plucky, determined cripple, struggling against adversity, Klara in Spyri's 'Heidi' (1995).

What is revealing is to discover how little distance has been travelled in over a century. In contemporary cultural texts including literature, film, marketing and ubiquitous charity advertising, for example, the same negative messages about disability and disabled people circulate. Disabled people are either freaks or objects of pity or wonder, never just ordinary people looking to get on with their lives.

Caravanning for the Disabled informs us that:

a disability need not hinder someone's enjoyment of touring and sightseeing, but rather enhance the pleasure of the experience and allow them to enjoy it more intensely. They also realise more clearly how limited their lives would be without the stimulus touring and travel provide (Caravanning for the Disabled, 2009)

In Andrew Collins' 2003 autobiography, *Where Did It All Go Right? Growing up normal in the 70s*, Collins tells us that:

Mrs Munro had a mentally and physically handicapped son called Steven whom she occasionally brought into school just to scare the life out of me (Collins, 2003:67)

The website report by *Thurrock Council News* of its Citizen of the Year Awards includes a list of descriptions of various of the town's disabled citizens saturated with words like *bravery, overcoming, living life to the full despite illness, special, inspiring courage, the face of adversity, overcoming personal difficulties, and sheer determination to overcome his disability* (Thurrock Council, 2005).

Images and representations such as these reflect and reinforce expectations which accept as common sense the idea that impairment is an undesirable attribute that blights the lives of those it affects : rather than being a relatively commonplace and usual part of human experience.

Disability Arts

Disability Arts are art forms, art works and art productions created by disabled people to be shared with and to inform other disabled people by focussing on the truth of disability experience (Masefield, 2006:22).

Disability arts emerged during the 1980's as the cultural wing of the disabled people's movement, a self-organised democratic social movement which campaigns for equality for people with impairments within a disabling society. The organising principle around which this movement united itself was the

social model, which re-defined disability and provided a framework which cast a different light on the problems of disability. In the social model impairment is identified as 'the loss or limitation of physical, mental or sensory function on a long-term or permanent basis'; while disability is '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' (Barnes,1994:2). Disability is not a flaw that individuals *have*. Rather, it is a relationship experienced by people with impairments in a society in which the distribution of resources and opportunities has been organized without taking their needs into account. People with impairments have experienced relegation to the margins of society and been provided with segregated 'special' services in a 'sheltered' world of 'care'.

As Carol Thomas (2002:20) notes, disability is 'the active and purposive social exclusion and disadvantaging of people with impairments, involving the social imposition of restrictions of activity and the socially-engendered undermining of their psycho-emotional well-being.' The disabled people's movement has argued that the problems of disability can be resolved if attention is shifted from attempting to cure or rehabilitate people with impairments to removing barriers so that they can participate on their own terms as equals within the social mainstream.

Colin Hambrook (2005) has suggested that the activities of the disability arts movement can be divided by decade:

During its origins in the 1980s cabaret and performance were prevalent. Throughout the 90s theatre and dance became a force to reckon with, with the emergence of companies like Graeae, Heart'n'Soul and Candoco. Over the past five years or so, film, media and the visual arts have seen a blossoming of work by disabled artists.

Disability cabaret created a point of connection and awakening for disabled people who, up until then, had been encouraged to believe that the most creative activities they could hope to pursue were dominoes and basket weaving. Johnny Crescendo's 'Choices and Rights' or 'Disabled People Aren't Allowed to Say 'Fuck'' (Holdsworth, 1989); Simon Brisenden's 'Scars' or 'Battle for the Elephant and Castle' (DAIL, 1992); Sue Napolitano's 'Hump' or 'Disabled Apartheid' (Napolitano, 1993); Ian Stanton's 'Chip On Your Shoulder' or 'We've Got Each Other' (Stanton, 1997): these songs, poems and performance pieces were the cultural accompaniment to a new political narrative on disability, a narrative written by disabled people which said that disabled people were not sad and pathetic but angry. "In a world that tells us we're shit because we're disabled, it's especially important that we have a unique place that provides peer group pressure and support," writes Mat Fraser (2004). The emergence of organizations such as the London Disability Arts Forum, the National Disability Arts Forum, the Northern Disability Arts Forum, Tyneside Disability Arts and the North West Disability Arts Forum supported and developed this activity.

Disability arts developed during the 1990s, taking on a professionalism which had little to do with performers wanting to 'overcome and prove themselves' and a lot to do with disabled artists being professional about their work. Common Ground Sign Dance Theatre, a company of Deaf and hearing performers, gained recognition for inventive and elaborate pieces using the gestures and textures of British Sign Language as foundations for works exploring Deafness – identified as an aesthetic experience – and the rejection of deafness as perceived by a majority culture restricted to thinking/communicating through the spoken word. Power, respect and control were the key themes underlying the work of Heart'n'Soul, a reggae band and performance group of people with learning

difficulties. 'Some people watching us are disabled people and they'll be thinking 'I wish I could do that'. We're teaching people how to be strong, and it's important for us to show other people that they can create their own stuff' (Delin, 1997:176).

Disability arts continues to flourish across a diversity of art forms: visual artists Cathy Woolley, Colin Hambrook, Lyn Martin, Aidan Shingler, Fatma Durmush, and Phil Lancaster; mixed media artists Tony Heaton, Brenda Cook, Juan delGado and Mark Ware; film makers Aaron Williamson and Philip Ryder; performance artists Deborah Williams, Jeni Draper, Jean St Clair, and Claire Cunningham; writers and stand-up comics Penny Pepper and Laurence Clark - and many others - contribute to the deepening of the exploration of the experience of disability which suggests that this is far from being simply about personal tragedy.

For many disabled people, attendance at a disability arts cabaret, performance or exhibition has been a moment of epiphany. To begin to understand that the negative experiences you thought were yours alone are shared and understood by others and to begin to understand that it is not you but the social environment around you that needs to change is a powerful awakening. When an artist can communicate these things in words or music or through dance or image, a sense of connection and solidarity is established.

Many disabled people who would never countenance handcuffing themselves to a bus or throwing themselves out of their wheelchair to block traffic have, nevertheless, become engaged with the broader politics of disability through disability arts. Jane Campbell (1996: 199) has likened the disabled people's movement to a jigsaw, 'each piece vital for the true picture to emerge'. At the Leonard Cheshire Red Feather celebrity ball in Manchester in 2002 a group of twenty disabled activists took over the party, letting off stink bombs and filling the banqueting suite with feathers whilst singing 'The bus driver abused me' and other disability rights protest songs (Cameron, 2007). In this scene, two pieces of the jigsaw, disability arts and the direct action network are seen coming together as part of a wider movement.

An Affirmative Model of Disability

Current charity slogans – 'Turning disability into ability' (Capability Scotland, 2006) or 'Looking through disability' (Playback, 2009) – reinforce the idea that disability is an unfortunate individual condition that can be overcome with caring intervention. It is implied that imprisoned inside the afflicted body of each disabled person there is a healthy, 'normal' person struggling to break free.

A colleague of mine who has cerebral palsy tells of how, growing up, he identified positively with the self within - the inner self through whose senses he experienced and through whose cognitive processes he rationalized - and rejected his c.p. as something with which he was burdened but that had nothing to do with making him *who he was*. As an adolescent I recognized myself as somebody who had been in a serious road accident, who had experienced brain injuries, talked slowly and had a bit of a limp, but I responded with anger to any suggestion that I was disabled (Swain and Cameron, 1999). Disabled artist Eddie Hardy tells of how, as a teenager he was 'still in denial about being disabled... and if I saw anyone who was disabled I didn't want to talk to them, and if I did talk to them it was as if I was able-bodied, doing the old patronising bit' (Shakespeare et al: 1996:51). Through coming into contact with the disabled people's movement and the social model, each of us is now able to say, with pride, "This is who I am." But things might have happened otherwise. Twenty-five years further down the line, young disabled people I worked with as a trainer recently made statements at the outset of the course along

the lines of: "I'm not disabled, me. I'm normal." "You feel sorry for the disabled kids. You want to help them" (LCIL 2005).

Subjection to dominant discourses means that people with impairments, rejecting disability identity, continue to struggle as individuals against structural barriers, believing both the cause and the solution to the discrimination they experience to lie within themselves. Very often this leads to disillusionment.

Through the development of the culture of resistance that is disability arts, disabled people have developed a discourse which rejects personal tragedy narratives and which identifies impairment as part of human experience to be valued on its own terms. A recent development in Disability Studies, which builds upon both the social model and insights generated within the disability arts movement, is an affirmative model which redefines impairment as: 'physical, sensory, emotional and intellectual difference divergent from dominant cultural norms, but which is to be expected and respected on its own terms in a diverse society'; and disability as 'a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of people identified as unimpaired' (Cameron, 2008).

Conclusion

The challenge to workers in the fields of community development and community arts is to identify which models of disability inform their own practice. What is required is not an avoidance of the term 'disability' or an uncomfortable, unconvincing pretence that everyone is the same; but an acceptance and equal valuation of difference and a recognition of and determination to address the barriers inherent in social environments. This means going beyond simply accepting people with impairments as individuals to acknowledging the ways in which disability is created through interactions, expectations, assumptions, remarks, ways of doing things. Not viewing Jimmy as being 'just like the rest of us', but recognizing Jimmy's impairments as an important part of who he is. Not compensating so that Jimmy can participate in what everyone else does, only not quite so well, but in changing the things everyone else does. It means allowing people with impairments to do things differently when they want without having to feel that doing things differently is not as good as conforming (Thomas, 1999:43).

Much use has been made within disability cabaret of Boal's Theatre of the Oppressed (1979; 1997). Forum theatre addressing disability issues is a good idea, though there are dangers involved in going down the simulation road (Swain and Lawrence, 1994). Focus on barriers rather than on impairment. Disability arts represents disabled people as strong, knowing, angry, proud, sexual, funny. It provides us with more positive representations upon which people with impairments can draw. Visit disability arts websites for ideas. www.ndaf.org or www.disabilityarts.com are good examples.

There is an important role for community development/community arts informed by the social model in acknowledging and exploring disability as a social construction in order to enable people with impairments and those alongside them to develop perspectives and identities which resist those offered by dominant culture. Community arts informed by the affirmative model is reflective practice which examines and challenges its own knowledge and understanding in order to break free of the shackles of normality and embrace difference.

References

Alliance for Inclusive Education (2006) <http://www.allfie.org.uk>

- Barnes, C. (1994) *Disabled People in Britain and Discrimination* Hurst. London
- Barnes, C. Mercer, G. and Shakespeare, T. (1999) *Exploring Disability: A Sociological Introduction*. Polity. London
- Boal, A. (1979) *Theatre of the Oppressed* Pluto. London
- Boal, A. (1997) *Games for Actors and Non-Actors* Routledge. London
- Cameron, C. (2007) 'Breve storia del movimento delle persone disabili nel Regno Unito'. *Rivista Sperimentale di Freniatria*. Vol. CXXXI. N. 2/2007. pp. 83-99. FrancoAngeli, Reggio Emilia, It.
- Cameron, C. (2008) 'Further Towards an Affirmation Model'. In Campbell, T. Fontes, F. Hemingway, L. Soorenian, A. and Till, C. (eds.) *Disability Studies: Emerging Insights and Perspectives*. The Disability Press. Leeds
- Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding Our Past, Changing Our Future* Routledge. London
- Capability Scotland (2006) Accessed at <http://www.capability-scotland.org.uk>
- Caravanning for the Disabled (2006) <http://www.caravansitefinder.co.uk/features/disabled>
- Collins, A. (2003) *Where Did It All Go Right? Growing up normal in the 70s*. London: Ebury Press
- DAIL (1992) *Disability Arts in London: the First Five Years* DAIL. London
- Darke, P. (1998) 'Understanding Cinematic Representations of Disability' in Shakespeare, T. *The Disability Reader: Social Science Perspectives* Cassell. London
- Delin, A. (1997) 'Heart'n'Soul' in Pointon, A. and Davies, C. *Framed: Interrogating Disability in the Media* BFI. London
- Dickens, C. (2003) *A Christmas Carol* Penguin. London
- Fraser, M. (2004) <http://disabilityarts.com/archive/features/mat-fraser/>
- Friere, P. (1996) *Pedagogy of the Oppressed* Penguin. London
- Hambrook, C. (2005) <http://disabilityarts.com/what-is-disarts/>
- Holdsworth, A. (1989) *Johnny Crescendo Revealed* Holdsworth. Manchester
- LCIL (2005) *It's Your Life* Lothian Centre for Integrated Living. Edinburgh
- Masefield, P. (2006) *Strength: Broadides from Disability on the Arts*

Trentham. Stoke-on-Trent

Napolitano, S. (1993) *A Dangerous Woman* Manchester GMCDP

Oliver, M. (1996) *Understanding Disability: From Theory to Practice* Macmillan. London

Playback (2009) <http://www.playbacktrust.net/>

Rieser, R. and Mason, M. (1992) *Disability Equality in the Classroom* Disability Equality in Education. London

Shakespeare, T. Gillespie-Sells, K. and Davies, D. (1996) *The Sexual Politics of Disability* Cassell. London
Spyri, J. (1995) *Heidi* Penguin. London

Stanton, I. (1997) *Rolling Thunder* Stream Records. London

Stevenson, R.L. (1998) *Treasure Island* Oxford World Classics. Oxford

Swain, J. and Lawrence, P. 'Learning About Disability: Changing Attitudes or Challenging Understanding' in French, S. (ed.) *On Equal Terms: Working With Disabled People* Butterworth-Heinemann. Oxford

Swain, J. and Cameron, C. (1999) 'Unless Otherwise Stated: Discourses of Labelling and Identity' in Corcoran, M. and French, S. (eds.) *Disability Discourse* Open University Press, Buckingham

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability* Open University Press. Buckingham

Thomas, C. (2002) 'A Journey Around the Social Model' in Corcoran, M. and Shakespeare, T. *Disability/Postmodernity: Embodying Disability Theory* Continuum. London

Thomson, R. G. (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* Columbia University Press. New York

Thurrock Council (2005) Thurrock's Heroes Honoured.
<http://www.thurrock.gov.uk/news/content.php?page=story&ID=1614>

Titchkosky, T. (2006) *Disability, Self and Society* University of Toronto Press. Toronto

Willis, P. (2000) *The Ethnographic Imagination* Polity. Cambridge