**Colin Cameron**

**Disability Arts: From Alienation to Affirmation**

**Disability arts and oppression**

I want to start by considering a statement made by the disabled poet and actor Alan Sutherland:

I don’t think disability arts would have been possible without disability politics coming first… Our politics teach us that we are oppressed, not inferior… Our politics have given us self-esteem. They have taught us, not simply to value ourselves, but to value ourselves as disabled people (Sutherland, 1997).

With Sutherland, I’d like to suggest that disability arts (in the UK at least) is fundamentally tied up with the wider disabled people’s movement and has no real meaning apart from the disabled people’s movement. In Campbell’s characterisation ofthe movement as a jigsaw, ‘each piece vital for the true picture to emerge’ (Campbell and Oliver, 1996:199) there are two images drawn. Just as each piece – the independent living movement, campaigning organisations, the direct action network, disability studies, disability arts – is required in order to understand the movement as a whole, so each part is given context only in relation to the whole. Disability arts involves creative and cultural production which interprets and illuminates the meaning of disability and the meaning of lived experience as people with impairments in a disabling society. Central to this enterprise is an understanding of disability as an oppressive social relationship, which ties us to the social model. The social model identifies disability as:

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, in Barnes, 1994).

Disability is not an embodied condition or characteristic, but an oppressive social relationship experienced by people with impairments in a society which requires conformity and standardisation. We are not people *with* disabilities, we are people with impairments who are disabled by the barriers we encounter on a daily basis in the business of going about our everyday lives.

Disability arts as a set of practices emerged in the 1980s in the

activity of disabled people forging a new sense of personal and

cultural identity illuminated by the social model: an identity

rooted in perceptions of self-worth and value rather than one

which could measure itself only in terms of physical deficit or

departure from dominant social and cultural norms.

Disability arts was issue-based arts, characterised and

motivated by anger at the social injustice experienced by

people with impairments in terms of exclusion from mainstream

education, employment, housing, information, public transport,

leisure opportunities. In Masefield’s (2006:22) terms:

Disability Arts are art forms, art works and arts productions created by disabled people to be shared with, and to inform other disabled people, by focusing on the truth of disability experience.

This anger, however, was not simply oppositional but

productive, for it strengthened the sense of common purpose of

disabled people coming increasingly to talk to each other

about their lives and the things happening in their lives. People

with different impairments who had traditionally been taught by

the charities, the celebrities, the doctors and the ‘caring’

professionals that their interests were separate and unrelated

began to recognise in each other shared experiences of

marginalisation and medicalisation.

Disability arts, then, has at its heart the principles of transgression, resistance and pride. It is transgressive in that it involves a refusal by disabled people to identify themselves in terms of personal tragedy as dominant culture represents and seeks to recognise them; it embodies resistance to hegemonic discourses of normality and abnormality; and it expresses pride by establishing physical difference as something to be cherished rather than turned away from.

In Sue Napolitano’s words:

But let me tell you

This body has been reclaimed

From the cold stares of strangers

And the eyes of doctors

In cream coloured rooms.

Been loved with kisses and caresses;

Given back to me whole.

(Napolitano, 1993:12)

**I’m in love with my body**

All of these characteristics – transgression, resistance and pride - can be discovered in a couple of lines penned by the blues singer and disabled artist Johnny Crescendo:

I’m in love with my body.

It’s the only one I’ve got

(Holdsworth, 1989).

There is a self-respectful defiance in these words and a refusal of expectations that, as a disabled person, Crescendo will only be able to relate negatively to his own embodied experience. Impairment is part of everyday experience, not something to be lamented. In talking about why he wrote the song *I’m in love with my body*, Crescendo tells of how during his formative years he had neither mixed with other disabled people nor felt comfortable with his impairment:

If I was sitting down and a potential girlfriend came up to me I would dread the moment I had to stand up. I met some disabled people but they seemed to be saying thank you and God bless you all the time and I didn't want to do that. This continued until my early 30's when I started to come in contact with disabled people who said fuck you instead of bless you and fuck off instead of thank you. I'd always been political and when the penny dropped it was so easy to see how I had been oppressed (Holdsworth, 2004).

Engagement with politicised disabled people – with disabled

people who had taken on the social model as a framework for

making sense of the contexts in which they lived their lives

– enabled Crescendo to throw off the internalised oppression

which had earlier meant he could only live uncomfortably with

his impairment. Donna Reeve has described internalised

oppression as existing

when individuals in a marginalised group in society internalise the prejudices held by the dominant group... This form of oppression is most effective when acting at the subconscious level, affecting the self-esteem of the individual in addition to shaping their thoughts and actions (Reeve, 2004:87).

When dominant culture offers only disabling images and

narratives of impairment as either to be pitied and suffered or

struggled against and overcome, the possibility of living with a

positive sense of the impaired self is made a difficult business.

As Cal Montgomery has noted:

Every few hours I run up against people who feel free to remind me that I’m their inferior and that I should conform to whatever they’ve decided ‘people like [me]’ are supposed to be like (Montgomery, 2006: unpaged).

When this cultural bullying is only ever experienced individually it is hard to identify disability as other than an individual problem. Stereotypes are pernicious because, in Young’s terms (1991:60), dominant culture’s ‘inferiorised images of the group must be internalised by group members at least to the extent that they are forced to react to behaviour of others influenced by those images’. They spoil life and place limitations on who it is possible to be and become, for if one always has to respond to prejudiced perceptions this interferes with, disturbs and alters the business of getting on with life. Young (1991:60) refers to DuBois’ concept of ‘double consciousness’ – ‘this sense of always looking at oneself through the eyes of others, of measuring one’s soul by the tape of a world that looks on in amused contempt and pity’.

Through the organisation and development of cabarets, festivals, exhibitions, performances and workshops (Sutherland, 2005), the disability arts movement created spaces in which disabled people could come together to share and explore with each other insights and perspectives on situations that had previously only been sensed as the inevitable outcome of personal deficit . As Elspeth Morrison and Vic Finkelstein have argued:

Arts events can provide another accessible route for looking at the world in relation to disabled people… Having someone on stage communicating ideas and feelings that an isolated disabled person never suspected were shared by others can be a turning point for many (1997:127).

With access at its heart, in practical terms this meant that disability arts gigs usually took place in small venues – arts centres, community centres, civic centres, sports centres, day centres, pubs, college bars, residential homes, any place disabled people were able to get into. It was experienced as a liberating and transformative experience to have disabled artists, singers, poets, theatre groups, bands, dance groups, stand-up comics on stage, drawing attention to the absurd behaviours of patronising professionals, council officials, over-protective carers and nosey do-gooders; laughing at cultural icons disabled people have been taught to hold in high regard; questioning infantilising social limitations imposed on disabled people.

Humour tinged with anger is a key ingredient of performance poems like Johnny Crescendo’s ‘Where D’ya Get That Leg?’(Holdsworth, 1989) or ‘Disabled People Aren’t Allowed to say “Fuck”’ (Holdsworth, 1989):

Disabled people are allowed to say help, please, thank you, thank you, thank you very much

But they’re not allowed to say ‘fuck’

But they do

The lyrics of Ian Stanton’s songs ‘Chip On Yer Shoulder’ (Stanton, 1989) or ‘Remember Douglas Bader’ (Stanton, 1992) involve laughing at professional advice to be happy with social roles as nodding, smiling, passive recipients of kindness:

You’ve got a chip on your shoulder Got a really bad attitude Is it any wonder That people treat you the way they do You really should be grateful For all we do for you And be a quiet little crip without a chip

The sketch ‘What We Really Think’ by the theatre group Get Off Our Backs (1998) takes a wry look at assumptions about normality and at the knots non-disabled people sometimes get themselves into over language in relation to disability. It discloses the insight that disabled people, comfortable together in their own bodies and with their own identities, do not always regard normality as something to aspire to. The sketch involves two disabled people sitting in a park talking to each other:

“Well, look at that! A normal person!”

“Don’t be cruel! They can’t help it. Do you want people to think you’re prejudiced?”

“No, I suppose not. So what should I call them?”

“Well, language is important. I would stick with non-disabled… tosser… prat…”

Using the insulting terms *tosser* and *prat*, the actors undermine the assumption that disabled people spend their lives wishing to be like the non-disabled. The standard view that disabled people are to be pitied for the tragedy of their impairments is reversed as it is disclosed that disabled people often pity the non-disabled for their conventionality. In Paula Greenwell’s words ‘People say to me wouldn’t you want to be normal and I say I wouldn’t want to lower my standards’ (in Swain, French and Cameron, 2003:106). To a disabled audience, the exchange above is funny because in a few lines it expresses something often felt but rarely spoken.

‘The Best Fake Charity Collection Buckets’ (2007) is a film shown by disabled comedian Laurence Clark. It shows footage of Clark in his wheelchair on a busy London shopping street with a series of increasingly bizarre statements printed on the charity collection bucket he is holding: ‘Pay off my mortgage’; ‘Please don’t put money in here, I will get a criminal record if you do’; ‘Sucker! This is a scam!’; ‘I am not a charity case’; ‘Kill the Puppies’. The humour lies in watching the variety and number of passers-by who, in spite of Clark’s protests, insist on putting money into his bucket. The film demonstrates the need felt by many non-disabled people to respond with misplaced sympathy to the appearance of impairment, revealing clearly also their unwillingness to actually listen to what disabled people have to say.

*Meet the Superhumans Part 2* (Araniello, 2012) is a satirical film in which, over incessant dramatic background music, Katherine Araniello appears, sweating, medal bedecked and wearing a track suit, spouting the kinds of cliched statements made with great frequency and intensity on television by disabled athletes during the 2012 London Paralympic Games. Her performance emphasises and mocks the tautological effect produced:

It was the toughest day of my life I had to dig deep to achieve what I have achieved And that was to be the best And I am the best

It was an amazing experience And I know that I have inspired a future generation

I want to say a big thank you To everyone who has supported me My family, friends, all of you, Thank you so much I couldn’t have done it without you

I never knew someone like me Could be of such sporting excellence And achieve what I have achieved I have set a legacy

Commenting on the film, Araniello states that:

I find the terminology that the Paralympians use repetitive and the opposite to inspiring. The sentimentality of heroic status is not an association that I personally adopt or want to be identified with (Araniello, 2012b.)

Araniello’s point was to satirise Paralympians’ use of ‘repetitive uplifting language coupled with the heroic sentiments of triumph over tragedy’ (Araniello, 2012b) to draw attention to the fact that, in spite of the fact that during the Paralympics there was heightened media focus on disabled people, this actually delivered nothing new (Cameron, 2014).

Disability arts, then, involves a rejection of dominant cultural narratives and assumptions which represent impairment as something to be cured, endured or overcome, a sign of misfortune whichever way it is considered. It involves revealing and reflecting upon the experience of disability as the experience of oppression.

It offers an alternative perspective. What is involved is a reclamation of the impaired body, a statement of the right of the impaired body to respect and inclusion on its own terms. Mitchell and Snyder have made the point that:

The power of transgression always originates at the moment when the derided object embraces its deviance as value. Perversely championing the terms of its own stigmatisation, marginal peoples alarm the dominant culture with a canniness about their own subjugation (Mitchell and Snyder, 2000:35).

Disability arts throws out a challenge to the ontological security of those who find comfort in their own normality. Building on an insight generated by the social model, disability arts unsettles dominant cultural ideas about the self and the autonomy of the self. It develops a discourse which regards impairment as presenting an opportunity to gaze critically and differently at what passes for reality: a reality which mediates the interests of the dominant non-disabled. It draws the unpredictability and frailty of the human body from the dark recesses of consciousness to which it has been confined and brings it to the forefront of attention.

**The Affirmative Model**

An intervention within the individual/structural debate around the social model (Thomas, 2007) was made by Swain and French (2000) in an article entitled ‘Towards an Affirmation Model of Disability’. Rooting their idea in perspectives emerging from the disability arts movement, the affirmation model was proposed as a critique of the personal tragedy model corresponding to the social model as a critique of the medical model.

The affirmation model was, Swain and French stated:

a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle of being impaired and disabled (Swain and French, 2000:569).

In proposing an affirmation model, Swain and French set out a position from which it could be asserted that, far from being necessarily tragic, living with impairment can be experienced as valuable, interesting and intrinsically satisfying. This is not to deny there can be negative experiences resulting from impairment, but to make the point that this is not all that impairment is about. While Swain and French made it very clear that the affirmation model builds upon the social model (rather than being proposed as an alternative) they suggested that the need for an affirmation model is established in that it is not a purpose of the social model to reject a tragic view of impairment:

even in an ideal world of full civil rights and participative citizenship for disabled people, an impairment could be seen to be a personal tragedy (Swain and French, 2000:571).

In my PhD research, *Does Anybody Like Being Disabled?* carried out at Queen Margaret University, Edinburgh (Cameron, 2010), I aimed to give structure to the affirmation model. While Swain and French had described what the affirmation model is *about* and what it is *like* (Swain and French, 2000:580) they had stopped short of specifying what it *is* (Cameron, 2008). One of my research aims was to enquire whether useful affirmation model definitions of impairment and disability could be fashioned in order that it could be used as a practical tool rather than remaining just a good idea. My research involved gathering and interpreting qualitative data gained through interviews and observations of everyday life experiences with sixteen disabled people from around Scotland and England.

Swain and French had identified a number of features by which the affirmation model is, and is not, characterised. The affirmation model is, they stated, about:

• being different and thinking differently about being different, both individually and collectively

• the affirmation of unique ways of being situated in society

• disabled people challenging presumptions about themselves and their lives in terms of not only how they differ from what is average or normal, but also about the assertion, on their own terms, of human embodiment, lifestyles, quality of life and identity

• ways of being that embrace difference

(Swain and French, 2008:185)

These descriptions are reflected in remarks by Lola, a wheelchair-user from London:

I haven’t been terribly well but… I’d rather be me than not be the whole mix... positive, negative, flawed, happy, sad mixture that I am... that makes me me… and, you know, you can play the sort of games with yourself, thinking… if you had that or you didn’t have that would it still make you who you were... and I don’t believe I would be the same person... (Cameron, 2010)

For Lola being a disabled woman is an experience she would not want to be without. While she acknowledges the sometimes uncomfortable reality of her impairment, she rejects the futile seductions of the ideology of normality (Oliver, 1996). She regards her impairment as a core part of her person, something without which she would not be who she is.

Swain and French (op cit.,) emphasised that the affirmation model is *not* about:

• all people with impairments celebrating difference

• disabled people ‘coming to terms’ with disability and impairment

• disabled people being ‘can do’ or ‘lovely’ people

• the benefits of living and being marginalised and oppressed in a disabling society

Roshni, a blind woman from Glasgow, remarked:

I’ve yet to meet anybody who is a hundred per cent happy with who they are... I don’t necessarily think that because you’re disabled you are extra unhappy with who you are... but equally I’ve yet to meet the person who’s jumping up and down, celebrating that they’ve got dodgy eyesight... but, having said that, it’s certainly not a cause for me to cry and weep and wring my hands and give up on the world... there are lots of things I’m not happy about... I’m not happy about the fact that I’ve got dry rot in the next room and the ceiling needs replacing... I think my visual impairment is on the same scale as that... life happens... (Cameron, 2010)

Roshni suggests impairment is something to live with rather than a source of perpetual distress. Her blindness is something ordinary for her, part of her everyday experience of life. She is realistic about her situation, recognising that to be blind does not make life any easier, but at the same time, she does not regard her life as a blind person as being one long worthless experience. She leads a busy and interesting life which she enjoys.

In that it involves a rejection of assumptions of tragedy, yet seeks to build on the social model, the affirmation model requires recognition of the oppressive contexts within which everyday life is experienced by disabled people. In my research, this was brought into focus by Charles, a wheelchair-user from Liverpool, who said:

...when I was talking in the pub with Erin and yourself tonight… with every sentence I wasn’t thinking oh, I’m going to say this sentence with a speech impairment… blah blah blah… now I’m going to say this with a speech impairment… blah blah blah… I’m going to move back, but I’m moving back in my wheelchair… you know… you don’t think… but… when you catch somebody looking at you… and looking at the effects of your impairment… concentrating on your impairment… then you’re suddenly aware that you’re speaking differently… (Cameron, 2010)

Charles’ point is that while impairment is not necessarily experienced as a problem for the person concerned, he finds it is often made a problem by other people. It is not the experience of impairment which is negative, but other people’s response to impairment. The problematising of impairment by those identifying as normal involves a transactional exchange which validates their own sense of self.

At its simplest, the affirmation model makes the point that impairment is not an unfortunate aberration or an undesirable deviation from a norm, but is a relatively common and ordinary part of human life. My data led me to propose the following affirmation model definitions:

Impairment: physical, sensory, emotional and cognitive difference, divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society.

Disability: a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal

(Cameron, 2014).

In *naming disability as role*, the affirmation model identifies disability as a productive as well as a restrictive relationship. It is not just about what people with impairments are excluded from and prevented from being, but about the kind of social actors they are required to become instead. This may involve performing disability as passive dependency or in terms of strenuous denial of the significance of impairment. Either part negates the lived experience of impairment and signifies the desirability of normality. Identifying disability this way, the affirmation model can be used as a tool for making sense of what is going on within disabling encounters and interactions, and as a resource for refusing to become what we are expected to become. Being okay about being impaired involves transgression, audacity and resilience.

**Conclusion**

As disabled people we’ve all been there. You’re getting on with life, caught up in the stream of what you’re doing, what you’re thinking, what’s going on. Then, from out of nowhere, some non-disabled person imposes themselves on your consciousness and brings back home to you the fact that there’s an enormous gulf between the self-you-think-you-are and the self-they-think-you-are. You’re busy relating to yourself as a complex, multi-faceted individual. They see you as someone whose most significant characteristic is that you’ve got something ‘wrong’ with you.

Like when Sarah, a young woman who’s a wheelchair user with cerebral palsy, went to a restaurant with her boyfriend, who’s also a wheelchair user, and had the occasion spoiled not only by the gazes of the other customers but by the waitress who expressed surprise that they didn’t have a ‘carer’ to accompany them.

Like when I had shown an official from the Sports and Arts Foundation to the building where his next meeting was at, and he reached into his pocket, drew out a pound and said “Here you are, son… Buy yourself some chocolate.”

Like when Donald, a blind man, was waiting to meet me at Chalk Farm tube station, standing having a cigarette, and a passer-by came up to tell him “You’re at Chalk Farm tube station,” and walked away again.

Like when Chris, after taking a minute or two to answer the front door, called to the postman halfway back down the path and received the reply “Sorry, mate, I didn’t realise you were in a wheelchair.”

Like when Alice, at the supermarket till, remembered she had forgotten her cherry tomatoes and hurried back to the fruit and veg section to get some, to find herself being asked by a stranger “What’s wrong with your leg?”

We’re taken aback at what’s been said and at the assumptions being made about us. It’s disconcerting, annoying, upsetting, and can be temporarily confusing as we try to figure out where they’re coming from and how to respond. It’s difficult, because often while the words themselves haven’t actually been intended to be offensive, the layers of meaning that underlie them carry a weight of oppression.  Yet it is during encounters like these, in the flow and flux of life, that each of us has to choose who we are and who we want to become.

We know that many disabled people internalise the values which oppress them and end up identifying their own embodiment as the cause of the unwelcome intrusions and banal comments they receive. It’s tempting to try and distance yourself from your impairment, to try and act as if this is something of minor significance to your life experience or something you’ve transcended. Alternatively, it’s possible to affirm impairment as a core part of who you are, and to scorn the oppression manifested in the microaggressions encountered in everyday life.

They’re the ones with the problem, not us. In order to achieve a relative security of identity, they have had to become part of what Heidegger termed a They, which involves being the same as everybody else, or in other words, rather mediocre. They can’t handle difference and that’s what makes them act like twats when they encounter disabled people. If you really get down to the bottom of it, it’s that they can’t deal with the fact that one day they’re going to die and at a deep level we remind them of that fact. That’s why they couldn’t handle PKN at the Eurovision finals. That’s why, to almost quote the lead singer of PKN, ‘they’re shitter than we are.’

As a development emerging from the social model, the affirmative model has its roots within the insights and perspectives developed within and by the disability arts movement. Whereas the social model allows us to understand the bigger picture, and to recognise the structural barriers which oppress and exclude, the affirmative model is intended to allow us to make sense of what happens at the level of the countless everyday interactions in which people with impairments are made to sense themselves as deficient. If this model can be used as a tool for resilience in the face of oppressive social relations then its usefulness is established.

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