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## Introduction

In this chapter I discuss the disability arts movement in Great Britain as an example of a self-organised, critically conscious community established with political aims. I consider disability arts' role in forging individual and collective identities grounded in a re-evaluation of the meaning of disability, explore ways in which disability arts have challenged dominant representations of disabled people, and illustrate my discussion by reflecting on poems by the disabled writer Sue Napolitano. I outline the affirmation model, a theoretical development expressing the distinct social critique emerging from disability arts, and conclude by summarising the significance of this analysis for community development approaches.

## Two views

I was talking a couple of months ago with a PhD student at Northumbria University about an event he had recently attended during the early stages of his research. This was a non-disabled research student with no previous experience of disability arts, who is developing research into community arts more broadly. The event he had attended had been held by a local disability organisation and had involved, among other 'turns', a woman with learning

difficulties performing the Judy Garland song 'Somewhere Over the Rainbow' from the 1939 Hollywood film *The Wizard of Oz.*

The performance had been, I was told, greeted with wild applause and admiration. Not having been at the event I can't say for sure, but having been at plenty of events like this one I feel fairly confident in suggesting that much of the admiration would have been mingled with appraisals such as "Isn't it marvellous what she can do *in spite of her disabilities…*"

In my mind I contrasted this event with another, held in the same local authority area in North East England twenty years ago, in 1994, by a theatre group of young disabled people, some of whom had learning difficulties and others who had various physical and sensory impairments. In front of local councillors this group had performed a number of self-written comedy sketches highlighting and satirising the council's recently-published community care plan, the near non-existence of accessible public toilet facilities, the pointless and mind-numbing activities provided at the local day centre, and the woefully inadequate provision of local accessible public transport. Leaving the stage at the end of the performance, one of the young disabled people turned to the assembled councillors and proclaimed "You're all a bunch of tossers!" This abusive line was unscripted, but nicely expressed the sentiments that had been conveyed in the sketches. I recall that the show was met with constrained rather than wild applause.

There are two pictures here of disabled people involved with local community groups, both involving performance and the arts. One of

these involves disability arts and the other does not. As Barnes and Mercer (2010:207) have expressed it, there is a crucial distinction between 'disabled people doing art' and the more overtly political 'disability arts'. In Masefield's (2006:72) 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.

The truth of disability experience depicted by the young disabled people's theatre group described above involved being regarded primarily as passive recipients of care; as people who, by and large, wouldn't be accessing public spaces and therefore didn't require accessible toilet facilities; as people for whom attendance at the local day centre would fill up a sizable part of their adult lives; and as people who didn't require access via public transport to the places everyone else goes to because they had 'special' buses instead.

It is important here to make it clear what is meant by 'disability experience' because this is key to the development of our understanding. My intention is that the experience of being disabled should be understood as different to the experience of being impaired. This requires a consideration of the meanings of these terms within the conflicting individual and social models.

While there are some differences in wording, both the individual and social models identify impairment as a relatively long-term physical, sensory, emotional or cognitive characteristic (Cameron, 2014a; Cameron, 2014b) that can be either congenital or acquired. It is in their definitions of disability, however, that the models diverge. Within dominant (individual or medical model) discourse disability is identified as 'something wrong' with the bodies of disabled people (Oliver, 1996). The World Health Organisation (WHO), for example, has identified disability as 'any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being' (WHO, 1980, in Cameron, 2014a) and as 'an umbrella term, covering impairments, activity limitations, and participation restrictions' (WHO, 2012, in Mallett and Slater, 2014). In other words, disability is identified as an individual problem to do with some people's bodies, regarded in terms of personal deficit and abnormality, as something to be cured, endured or overcome.

The social model, developed initially by the Union of the Physically Impaired Against Segregation, challenges this dominant view by identifying disability as an unequal social relationship. Within the social model disability is 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities' (UPIAS 1976:14). This definition was broadened by Disabled People's International in 1981 (in Barnes, 1994:2) to include people with sensory, emotional and cognitive impairments. Here, 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'

From a social model viewpoint, disability is not something people *have* (we are not people *with* disabilities), but is something *done to* people with impairments. People with impairments are disabled by poor or non-existent access to the public places where ordinary life happens and by the condescending or unwelcoming responses of those who occupy these places. 'Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.' (UPIAS, 1976:14)

The sketches performed by the young disabled people did not attempt to ignore or shy away from talking about disability issues, but confronted them head on, challenging mainstream assumptions around what disability was all about. In expressing their dissatisfaction with the state of things in their own local authority, this group was part of a wider movement of disabled people collectively organising to bring about social change and to gain control over their own lives.

**The disabled people's movement**

> I don't think disability arts would have happened 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, 1989:159).

Sutherland's comment here describes the close relationship between disability arts and the wider disabled people's movement. The relationship between the different parts of the movement can be described as symbiotic, for each gives meaning to the others and has enabled the others to grow and develop. In Campbell's words 'The movement is a jigsaw- each piece is vital for the true picture to emerge' (Campbell and Oliver, 1996:199).

During the late 1960s disabled people were beginning to collectively question the legitimacy of large charities to speak on behalf of and organise the lives of people with impairments. Charities began to be identified as part of the problem of disability rather than as part of the solution. The work of disabled activists like Paul Hunt, an inmate at a 'care' home run by the Leonard Cheshire Foundation, led to the formation of the Union of the Physically Impaired Against Segregation (UPIAS). UPIAS was established as a forum for debate about disability issues by disabled people living in residential homes, and rejected the idea that organisations *for* disabled people - led by non-disabled people - were able to comprehend or promote the best interests of disabled people. While UPIAS' key aim was the eradication of all segregated homes perhaps its most important and lasting contribution to the development of the disabled people's movement was the establishment in 1976 of definitions of impairment and disability that would become known as the social model (Barnes, 2014). This framework for understanding became established as the big idea underpinning the emergence of new organisations *of* disabled people during the 1980s and 90s: local coalitions of disabled people campaigning about issues including access, housing, transport, employment, information, leisure; centres for independent living campaigning for, and later delivering, direct payments so that disabled people could employ their own personal

assistants and take control of their lives; organisations campaigning for the closure of segregated 'special' schools and demanding inclusive education; networks of disabled people conversing nationally under the umbrella of the British Council of Organisations of Disabled People (Cameron, 2014c). It is against this background and within this context that the emergence of disability arts needs to be considered.

**Disability Arts and Identity**

Day has suggested that, rather than being thought of as something 'natural', 'real' and 'out there' to be discovered and analysed, community can be regarded as a construct which is the outcome of human reflection and agency:

> If they are not to be treated as taken-for-granted facts within the social landscape, then communities have to be seen as resulting from some form of creative process, through which they are built and maintained. This implies that they have a history and trajectory of development, and that there will be continuing processes through which their existence is reproduced (Day, 2006:156).

Talking about the disabled community provides a good opportunity to consider this understanding of the term. Prior to the establishment of the disabled people's movement – in itself an elusive description beyond the organisations by which it is constituted (Campbell and Oliver, 1996) – it could easily be disputed whether such a thing as 'the disabled community' existed. Certainly the establishment of a community of self-identifying disabled people organising and

coming together to collectively campaign for equality faced considerable challenges. Perhaps the most important of these had to do with conventional views regarding disability as a 'discreditable' identity that few would willingly own (Goffman, 1990; Cameron, 2014d).

Pressures to discourage people with impairments from identifying collectively are embedded within everyday life practices, not least by the representation by large charities – organisations *for* rather than *of* disabled people- of disability issues as impairment-specific. While the organisations of the disability industry relied for income generation on the identification in the public mind of disabled people as pathetic cases in need of charity, each impairment – cerebral palsy, Down's syndrome, blindness, deafness, MS, epilepsy, and so on -was depicted in terms of its awfulness and its devastating impact on the lives of those so 'afflicted'. There was little reason for people with different impairments to seek association, and many reasons for avoiding each other. The requirement to play roles as passive, grateful recipients of others' kindness led many disabled people to be hostile towards the idea of identifying as disabled and to shun contact with other disabled people for fear of contamination by association. While community development discourse centres around ideas of collectivity, self- and mutual determination, the role of charities in preventing the development of a politicised disabled community and identity is clear. Those who identified disability as a social justice issue and campaigned for rights not charity were labelled as *complainers... who cannot deal with the problems related to their disabilities*

(Murphy, 2005:161). As is often the case when marginalised groups begin to identify oppression within existing social arrangements, powerful groups with vested interests in maintaining these structures find it easy to ignore or dismiss these claims as unrealistic and misguided.

From its appearance in the early 1980s through the work of companies and agencies such as Strathcona, Graeae and Shape, disability arts took an oppositional stance to these dominant representations. The London Disability Arts Forum (LDAF) was established in 1986 as a space in which disabled artists could engage creatively and communally in re-creating cultural meanings around disability, re-writing stories around disability, and producing new and challenging images of disability. Through the work of LDAF and other disability arts organisations which came into being in the following years – e.g. the Northern Disability Arts Forum, the National Disability Arts Forum, the Southwest and Northwest Disability Arts Forums - disabled people became involved in forging new individual and social identities based on pride and the celebration of difference.

Cabarets such as LDAF's The Workhouse were ground breaking in providing accessible spaces where disabled people could come to enjoy performances by other disabled people. Through music and song, theatre, dance, visual arts, photography, creative writing, film, sculpture, disabled people explored the experience of living with impairment in a disabling society. Disabled artists used anger, passion, humour and satire to reveal the oppressive nature of disability as a social relationship, to expose the oppressive

behaviours and assumptions of non-disabled people and to shed light on the way that disabling relationships were constructed in everyday interactions. Morrison and Finkelstein (1994:127) noted that attendance at a disability arts event could be a radicalising experience:

> 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.

The cabaret events organised by the DAFs became a key focus for community development, consciousness-raising and the development of collective as opposed to individualised identity. Disabled people came together to learn from each other and began to understand that the disadvantage they experienced was not the natural consequence of impairment, but was created by a world which rejected impairment. For many this meant emancipation from internalised oppression experienced in a culture where previously they had only ever seen themselves represented as undesirable and abnormal (Reeve, 2014). A process of 'coming out' as disabled meant becoming able to affirm self and to name society rather than self as being where struggle was required (Swain and Cameron, 1999).

Day (2006:154) has noted that:

> communities are brought into being through the interpretive activities of their members, and registered among the concepts which they use in their everyday talk and interaction.

In this sense, it is legitimate to talk about a disabled community having been intentionally created through the activity of disability arts. When, through the development of new narratives, people with a range of impairments collectively identify as disabled on the basis of having been excluded from active participation within ordinary life, a sense of belonging and relationship emerges, as well as the suggestion of a collective response and activity:

> By modifying the frame from one of innate deviance to one of oppression, individuals may come to feel angry not only because the system is unjust but because they have been made to feel ashamed... The activated feeling of anger propels stigmatized individuals into public space to behave collectively, and feelings of pride emerge (Britt and Heise, 2000:257).

Disability pride was the principle underlying the increased visibility of disabled people who demanded access to the social mainstream and an end to discrimination. From the early 1990s disabled people organised non-violent demonstrations which led, for example, to the end of ITV's annual Telethon charity fund-raising event; to the provision of allocated spaces for wheelchair-users on buses and trains; and to the establishment of anti-discrimination legislation. This is an example of community development involving commitment to an ongoing struggle for equality and demonstrating the possibility of making gains.

In Day's (2006:154) terms, community plays a key role in how people think about themselves, their personal and social identities, and their subjectivity. As Brown (2003:38) has remarked, 'Social change, though serious and vital, can also be uplifting'. For individuals with impairments, strength is found in being part of a community which rejects mainstream requirements to hide impairment and instead affirms and unashamedly flaunts impairment. What emerges is the recognition of the right to active participation in society's institutions without having to pretend to be something that you're not.

Ferguson (2009:67) has stated that:

> All identities are simply conventional ways of seeing things, of describing and arranging things and of behaving in relation to them. All identities are, ultimately, arbitrary and reside wholly in the attitude of a community for whom such an identity is taken to be 'real'.

To identify positively as disabled involves collective identification with other disabled people on the basis of being people with impairments who share a certain way of knowing and relating to the world. It involves an affirmation of self and an acknowledgement of the processes and barriers through which disability is reproduced in everyday life, as well as a commitment to challenge these in everyday life practices.

**Sue Napolitano**

Sue Napolitano (1948-1997), a disabled writer and performer in cabarets organised by The Greater Manchester Coalition of Disabled People in the early 1990s, used performance poetry to explore

experiences of self, embodiment, and disability. Her poem *Hump* (1993a) begins with a series of statements in which she makes her audience aware of her own knowledge of, and hurt at, having spent her life as the butt of other people's jokes. As the poem progresses, however, she becomes defiant: 'This body is where I live my life.' It is a statement of affirmation which finishes by throwing out a challenge: 'Don't make me a symbol for things you don't want to face.' The final verse anticipates Shakespeare's (1997) description of disabled people as 'dustbins for disavowal', onto whom are projected the anxieties of non-disabled people, perpetually anxious to deny their own mortality and physicality.

*Hump*

> I hear you snigger when I say
> HUMP
> Do you think I hadn't noticed
> The shape of my own back?
> Do you think I didn't wince
> When as a child they said
> "She's got the hump"?
>
> Do you think I didn't hide in the deep silence
> Of unspoken thoughts?
> Do you think I didn't learn fast
> That in England
> To be straight is to be good?

Did you want me to carry on the pretence?
Like a child disowning its mother
Distance myself and claim
"It's nothing to do with me
Must belong to someone else
Don't know why it keeps tagging along behind me."
Are you annoyed that I've broken the silence?

Do you know how long it took me
To say HUMP in public?

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.

This body is where I live my life.

So don't make me a symbol
For things you don't want to face,
Your passions,
Your fears,
The messy bits of life.
Find a way to accept the unacceptable in yourself,
And let my body be.

Napolitano's poem is startling, audacious, and transgressive because it flies in the face of non-disabled assumptions about the way disabled people feel about their bodies. This is a voice which refuses any longer to be oppressed or to collude in its own oppression. As poetry it works as a politics in its own right in that it both makes political demands and seeks to mobilise community into being, urging activity.

In *Let's Demonstrate* (1993b), Napolitano outlines a list of expectations about disabled people, who are meant 'to be aware of ourselves as disabled in the same way that (the non-disabled) are about us, and to have the same attitude to it' (Morris, 1991:19). Napolitano is here speaking from experience, and about things that will resonate with other disabled people. Disabled people are meant to experience their lives as burdens and to have a keen sense of their lives as tragic. They are meant to passively accept their lot and to put up with second-rate lives on the margins of what is going on, rather than being actively engaged as participants. Importantly, they are not supposed to understand disability as oppression: *You're not supposed to know that you've been short-changed* or to *gather with other disabled people*. For it is when disabled people begin to come together on their own terms that they begin to single out elements from their 'background awareness', reflecting on these, making them objects of consideration and objects of action and cognition (Freire, 1974:56). This kind of activity leads to an altered subjectivity and ends up in what Linton (1998) has termed 'claiming disability'.

*Let's Demonstrate*

You're not supposed to be happy
Just cheerful all the time.
You're not supposed to have a proper job
But packing screws for peanuts is O.K.
You're not supposed to have friends who like you for yourself,
You're not supposed to have lovers,
Just carers who get paid to care.
You're not supposed to have children
How could you, it would be so unfair on them,
And anyway, you're not supposed to have sex.
You're not supposed to go where you want, when you want
With whom you want, to do what you want.

You are supposed to be miserable
But putting a brave face on it.
You are supposed to be resigned to your fate.
You're supposed to be shut out, shut in
Isolated, lonely, dependent,
And, if at all possible, pathetic.

You're not supposed to be angry, pissed off, make demands.
You're not supposed to know that you've been short-changed for centuries.
You're not supposed to gather with other disabled people
To show that you've had enough of not enough.
You're not supposed to be strong.

But we know different, don't we?

In the poem's last line *But we know different, don't we?* Napolitano becomes confidential. She is addressing other disabled people directly. She is telling it like it is and giving voice to thoughts till now unspoken. The title *Let's Demonstrate* suggests what needs to be done. Disabled people must refuse what they are supposed to be.

In *Disabled Apartheid* (1993c) Napolitano draws attention to the way that barriers in the built environment exclude disabled people from participation as equals in ordinary life. Her thinking here is similar to that of Young (1990:41), who described oppression as:

> the disadvantage and injustice some people suffer not because a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society.

When Napolitano writes *Not that it was deliberate, you understand/They were far too nice for that,* she draws attention to the way in which injustice is masked as sympathy so that its perpetrators cannot recognise it for what it is. She identifies the meddling do-gooding and professional interference of the non-disabled towards disabled people as misguided and unwanted, when what is really needed is environmental and structural change to remove disabling barriers.

*Disabled Apartheid*

The municipal might of Victorian architecture-
No need for a sign saying

CRIPPLES KEEP OUT
When triumphal stone flights
Of stairs
Smugly bar the way to
The art gallery
The library
The committee meeting.

Not that it was deliberate you understand,
They were far too nice for that,
They simply forgot
To think that we might want to
Get in
Take our share
Play our part
Claim some space
Perhaps they had in mind
That our place
Was outside
With begging bowl in hand.

There is anger in these lines at the discrimination experienced by disabled people who have experienced segregation in a world of day centres, care homes, hostels, sheltered workshops, clubs for 'the disabled' – and told that there is something wrong with *them* -while being denied access to public spaces. Napolitano offers a critique of what may pass for community development – although perhaps more appropriately conceived as community-based services -  on the

edges of the mainstream, based on top-down, paternalistic assumptions about what disabled people need.

Napolitano's writing needs to be recognized as part of a body of work by disabled artists collectively engaged in shifting disability discourse. While a comprehensive survey of disability artists is impossible here, I want to highlight the work of a number of other UK artists to demonstrate a line of continuity and committed purpose. Simon Brisenden's (1987) poem *Scars* addresses medical paternalism, sexism, normalisation and power inequalities (Sutherland, 2008). Blues singer Johnny Crescendo's *I Love My Body* (1989) makes the point "It's the only one I've got," as a retort to those who expect disabled people to view themselves as tragic cases (Cameron, 2009). Folk singer Ian Stanton's (1989) *Chip On Yer Shoulder* pokes fun at various representatives of non-disabled petty officialdom and questions the ability of the non-disabled to see beyond stereotypes (Cameron, 2009). Sculptor Tony Heaton, in his 1991 work *Shaken Not Stirred* created an emphatic response to the charity industry when he brought a 7-foot high pyramid of 1760 charity collecting cans crashing to the ground by throwing an artificial leg at it (Sutherland, 2008). The Fugertivs were a disabled punk band who accompanied Direct Action Network demonstrations with raucous songs including *Let's Riot* (1999) and *The Bus Driver (Abused Me)* (1999) (Cameron, 2009). *The Best Fake Charity Collection Buckets* (Clark, 2007) shows footage of stand-up comedian Laurence Clark on a busy London shopping street. A series of increasingly bizarre statements are 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 number and variety of passers-by who, in spite of Clark's protests, insist on putting money into his bucket; also in being able to observe the unwillingness of the non-disabled to actually listen to what disabled people have to say (Cameron, 2014e). Aaron Williamson's (2009) *Barrierman* shows Williamson, dressed in a high-visibility health and safety jacket, placing security tape and traffic cones across rights of way in a busy Liverpool shopping area in order to highlight the inconvenience caused by unnecessary and random barriers to public access. Katherine Araniello's *Meet the Superhuman Part 2* (Araniello, 2012) satirises the tautological triumph over tragedy drivel spouted by disabled athletes during the 2012 London Paralympics and their endorsement of individual model views of disability (Cameron, 2014e).

**The affirmation model**

The critical politics of disability arts has always been at their core in that a demand for access to the mainstream has been central to what they have been all about. An additional, and perhaps unintended outcome, however, has been the development of a disabled aesthetic and a realisation of how bland a place the mainstream actually is. The mainstream requires conformity and standardisation, which is why it has marginalised difference. Disabled people, having owned

impairment, have spoken about the value their lives have gained through the experience of impairment, of an enhanced understanding of life. A perception has emerged that it is not they who need to change in order to fit the mainstream but the mainstream which needs to broaden and become less confining in order to include them. These insights have led to the development of an affirmation model (Swain and French, 2000; Swain and French, 2008; Cameron, 2011; Cameron 2014f) and definitions which express the distinctive social critique generated within disability arts:

> Impairment: physical, sensory, emotional and cognitive difference 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 identified as normal.
>
> (Cameron, 2014f:28).

In defining impairment as difference, the affirmation model avoids negative evaluative judgements in terms of 'loss', 'abnormality', or 'limitation'. This is not to say that impairment doesn't sometimes, often even, involve pain or discomfort, but is to make the point that this isn't all it signifies. The affirmation model identifies impairment as an important part of people's identities, to be owned as part of who they are, and not as something to be hidden or regarded as a source of shame. Community development practice needs to find ways of ensuring that impairment is regarded as an ordinary part of

human experience and acknowledged and included on that basis; rather than as something to be pitied, avoided, overlooked, tolerated or condescended to.

The affirmation model enables us to think about disability in productive terms. It is not just about what people with impairments supposedly cannot do and be, or are prevented from doing and being, but about what society requires them to do and be instead. Whether this involves taking on roles as passive recipients of others' benevolence or demonstrations of the unimportance of impairment, either negates the lived experience of difference and signifies the desirability of normality. Disability is a role which requires that people with impairments are unable to relate other than negatively towards their impairments, in order that the advantages of conformity are evident to both disabled and non-disabled people. It allows no room for the radical position which regards impairment as an ordinary part of life. The affirmation model provides a tool to be used in recognising and making sense of disabling assumptions, encounters and practices in everyday life.

**Conclusion**

The line of continuity identified above might give the impression that disability arts is flourishing. While there still exist some excellent examples of organisations up and down the country – e.g. Disability Arts Online, Shape London, Dadafest – disability arts has always had to contend with the difficulties involved in taking up a position opposed to views unquestioningly accepted by the majority. Masefield (2008) proclaimed the death knell for disability arts when

the Arts Council of England announced the termination of its grant to LDAF and five other disability arts organisations. This meant the closure of the UK's only national disability arts magazine – Art Disability Culture – and an end to the country's only disability film festival. The shift of focus from promoting equality to diversity as a funding category, along with the continued entrenchment of neoliberal thinking, has meant that overtly leftist arts have become unfashionable.

Apart from this, the weight of individual model thinking has meant the establishment of disability arts as a politicised cultural activity was always going to be a struggle. Bowditch, a disabled dance artist, for example, has recently commented on her performance piece *Falling in Love With Frida* "It's not about disability, it's about art" (InVisible Difference, 2014). In seeking to disassociate her work from disability, Bowditch is expressing a predictable, if naive, aspiration. We are returned to 'Over the Rainbow' and to Barnes and Mercer's (2010:207) description of 'disabled people doing art'. While there is no criticism to be made of disabled people – like anyone else – just 'doing art', the potential of politically naive cultural activity to bring about social progress is negligible. Its danger lies in its potential to reinforce reactionary social relations and to play a part in sustaining inequality.

While the values of community development involve commitment to principles of social justice, the limitations of its practice are highlighted by considering ways in which – in spite of intentions – it may unconsciously entrench oppressive social structures. The social model analysis developed by the disabled people's movement and

the affirmation model analysis emerging from the disability arts movement have importance in this context in offering critical perspectives for reflection on the potential of community development practice to be emancipatory.

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