**What to do? By Vic Finklestein**

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**Introduction Square:** Vic Finkelstein argues that the lack of involvement at the grassroots of the disabled people's movement, in debates and decision-making, can be traced to a right-wing disability elite, intent on maintaining an impression of unity whilst pursuing parliamentary pressure group politics. A politics remarkably in-tune with New Labour’s market principles. He further argues that a thorough engagement with disabled people at the grassroots and the formation of new alliances are required, if the dominant values of society are to be challenged and the material conditions of disabled people changed.

In my paper **Outside, Inside Out**[[1]](#endnote-1) published in the April 1996 edition of **Coalition** (first presented in an edited version in **Disability Now**[[2]](#endnote-2), April 1996) I argued that the increasingly insipid portrayal of disability issues on television reflected the lack of inspiration coming out of the disability movement. I deliberately made this criticism on a public platform beyond the control of an emerging overconfident and censorious right-wing disability elite. I wrote:

“As I see it the leading edge of the disability movement (through its important national and local organisations of disabled people and recognised disabled public figures) has not only lost its vision for change during the past five years but has, with what seems to be increasing momentum, actually been moving backwards.”

My reading of the signs were that changing conditions, out there in the **objective** social world, were not being analysed by subdued left radicals participating in grass-roots organisations. In the meantime, the movement was increasingly guided into “parliamentary pressure group politics” (in 1989, Richard Wood[[3]](#endnote-3) tells us in Disability Now April 1996, BCODP made “the campaign for comprehensive anti-discrimination its top priority.”)

This shifting focus was complimented by an attempt to **rectify** (in Tom Shakespeare's[[4]](#endnote-4) memorable words) the social model of disability so that there is more emphasis on the importance of personal **experience** in deciding appropriate campaigns. The **rectifiers'** inward focus was making it more difficult for people to see the connections between what happens inwardly in the disability world with the outward unfolding changes in the global market.

In practice, this meant the British disability movement was increasingly adopting policies which were believed to advance our emancipation but were actually in harmony with “New” Labour's adoption of market principles in all significant levels of life - most notably in the national health and welfare sectors where privatisation could proceed more swiftly and unchallenged. In these circumstances, disagreements between the “left” radicals and “right” **rectifiers** within the movement needed to be brought into the open.

While in general the direct and indirect feedback following the publication of my paper was very positive, going public like this touched a very raw nerve in at least one very irate “leader” and I was severely rebuked in the following way in a letter I received:

**Letter to Vic: “**... yes, we need to debate our future path and goals.... some of us do confuse personal journeys with political and social emancipation, but... let us debate from within and remain strong...”

and then adding this offensive attempt at a put-down:

**Letter to Vic: “**I would have thought your academic training would have demanded a full grasp of the facts before presenting such a line?”

Arrogantly assuming that I didn't know what was going on in the movement the letter-writer said I ought to have checked out:

**Letter to Vic: “**what we have been up to in the past four/five years before writing [my] critique of our so-called parliamentary obsession”

This was followed by a list of the leadership's achievements and, without any obvious awareness, this classic example of how they were assigning an empty and meaningless role to the grass-roots yet again:

**Letter to Vic: “**We have established a regionalisation structure and programme[[5]](#endnote-5) with 3 paid consultants whose prime function is to develop the grassroots, so they can do exactly what you are calling for in your article - **influence social policy and practice**, from a disability rights and social model perspective.” (my emphasis)

So, the function of the grass-roots is to act as an **influence** - but isn't this **exactly** the same attitude to “pressure group” politics which was exploited by the **Disability Alliance**[[6]](#endnote-6) in the 1970s (arising out of the failure of DIG) who wanted to use the grass-roots to influence legislation on benefits? The question is “whose policy and practice are we supposed to influence?”

Parliamentarians with abilities, community care workers with abilities, service providers with abilities, local authority managers with abilities? This is **not** what I called for! We need to influence and guide the policy and practice of disabled people!!!

I replied to the leader's letter in detail, pointing out that while the “leadership” may feel things are going well my contacts do not express the same satisfaction with what is happening in the movement. Personal experience is not a criterion for guiding a movement.

I wrote:

**Vic:** “There is always a danger of erroneously believing that our own experiences, influenced by the actions and ideas of those amongst whom we circulate, are the reality for everyone, regardless of whether they agree or not. While I do not question the veracity of all you say about your experiences in BCODP, I do question the validity of ascribing interpretations from this experience to the general situation. It simply does not square up with my own experience (which, in a sadly elitist way, you seem to have assumed is limited because it is not part of your circle of experiences in the movement). This experience is fed by a different circle of activists and a reading of the signs. For some time now individuals have mentioned worries about BCODP to me...”

I don't believe that the movement can “remain strong” given that its “top priority” does not sort out and support a long-term strategy which progressively engages the grass-roots in transforming **its own** material conditions of life. The only things that will remain strong are the illusions of unity and real worries about the direction that the movement is taking. We have to contrast BCODP's record with, for example, DAN's[[7]](#endnote-7) “direct action” and the disability arts movement where disabled people are engaged in changing their **own** lives. All disabled people need the opportunity to determine the direction of our movement. This is why in my reply I concluded:

**Vic:** “What for you, then, is merely an ill-considered choice [of publication] for airing my 'dissatisfaction with our Movement' is for me the first salvo in the defence of our Movement.”

Sadly, I only received a very brief reply which included this admission:

**Letter to Vic:** 'Thank you for giving me such a lengthy and considered response to my (rather hurried) letter of concern re. the DN article.'

Nevertheless, I felt it necessary to write again and point out that creeping elitism is often associated with thoughtless hasty judgements. This is because in the belief that they know best (reinforced by public attention and awards from people with abilities) the elite becomes increasingly careless about understanding the views of other disabled people.

**Vic:** “Following my detailed reply, which I hope at least partially clarified the place of my criticism within a strategic view of the struggle for emancipation set some 20 years ago with Paul Hunt and other UPIAS members, it turns out that it was in fact your response that had been somewhat less than thoughtful – a “rather hurried” letter of concern written in the “heat of the moment”'. While I do agree with you that ‘there is indeed a great deal of “missing information” between us – on both sides...” “I am convinced that the tendency to be hasty in dismissing other people's views, when these do not accord with narrow personal experiences, is a symptom of creeping elitism.”

I mention this correspondence to illustrate how an elite's needs can come into conflict with the grass-roots needs. The “leadership” may need to present a united front to the power structures controlled by people with abilities but how can an increasingly alienated grass-roots “debate our future path and goals” **without doing this in public?** The reality is that the disability “leadership” has “never had it so good.”

This is both in their own access to lucrative jobs and attention from the sources of political power. On the other hand, disabled people and health and welfare workers are increasingly stressed by the “modernised” services. Alongside this is the escalating power of lawyers as they regulate our access to “rights” in the market system (shifting dominance from the “medical model” to the “legal model” of disability).

Take direct payments as an example. This was supposed to be a great victory for the movement's campaigning (meaning the leadership's lobbying of parliament). But is this a victory for disabled people gaining more control over our lives or a victory for the private market system replacing the British socialised services?

Money, it should be pointed out, is a very flexible “means of exchange” for goods and services: it can be used **both to enable or reduce access** to resources. People need to know that direct payments provided by local and national government can easily be reduced in value in a variety of ways. Simply keeping the level of a benefit unchanged for a couple of years will allow “inflation” to do the trick of cutting the value of an allowance before people fully realise this is happening.

Similarly, breaking the link between a benefit or allowance and wages effectively reduces a payment received (this is what is happening with pensions and, we recently learnt, reduced the standard of living of an extra 100,000 pensioners under New Labour). Monetary allowances can also be taxed according to a variety of scales. More significantly for us, charging disabled people who receive direct payments for “care” is very effective way of reducing local authority costs.

Disabled people who rely on personal assistance for their daily living and are charged are forcefully being impoverished. This is somewhat like providing a child benefit, then making education compulsory for children and then charging for attending school - i.e. the user is actually given no real choice because they are forced to use a facility and then forced to pay for it.

Disabled people who receive personal assistance paid for by a local authority or rely on direct payments for personal assistance have few choices when they are charged. I was recently informed that my borough was imposing huge charges for my “care” which I simply could not afford. I faced the following choices:

1. I could try and pay the full charge as my donation to the salaries of people with abilities who manage 'care' services in the borough. I would have to do this by never having another holiday; I would have to reduce my food consumption substantially; cancel the insurance on my home and stop all house repairs and household appliance ma intenance. Even this would not cover the charges.

2. Alternatively, the “care” service hours I currently receive could be cut by over half. The saving achieved by this could count as my payment towards the borough's charges. I would, of course, then have to spend the rest of time, when I should have received assistance, in bed.

3. Finally, I could be given the name of a doctor who practices euthanasia for disabled people whose quality of life is unacceptably poor. This would reduce the burden of “care” suffered by people with abilities and save them substantial money.

Euthanasia, then, only becomes an issue in a definite context. For taxpayers, disabled people can easily come to be regarded as an expensive burden, especially in a national culture where individualism and independent living are highly regarded as virtues. Yet the discussion in our movement on this subject, and genetic engineering generally, has consistently been raised as if it is isolated from the increasing emphasis on rugged independence within a competitive market system[[8]](#endnote-8).

In truth the market economy treats human beings as if they are a harvest for consumption in the creation of wealth. In this culture disabled people can be seen as an imperfect “crop” which is surplus to the needs of the economy and should either be culled or genetically modified. We simply don't meet quality control standards.

In defending ourselves from such attacks, civil “rights” and “charters” are clearly not long-term safeguards. At best they offer temporary protection. At worst they create illusions about social security, elevating lawyers up a rung in the ladder of professions who administer control over our lives. The disability movement's response to euthanasia and genetic modification should see these events within the broad social context; not merely as disability issues.

On this subject, we have much in common with others who are concerned about genetic engineering and the production of crops solely in commercial terms. We need to educate such people that human beings are just as vulnerable to genetic manipulation to meet labour market standards as is the farmer's field for the supermarket. We need to learn from them, too, about resisting the harnessing of science for profit rather than to improve the quality of life. We need to campaign **with** them. We can only facilitate such an interaction by breaking out of the “special” prison in which we have been incarcerated and expanding our target for social change. The rectified “social model of disability”, aspirations of “independent living” and a reliance on “civil rights” prevent disabled people from taking **a leading role** in changing the dominant values of society.

Instead, the uniquely British approach to disability issues is dumbed down into a U.S. clone (without their historical safeguards). We should recall that in the USA the social model of disability means “the social consequences of having a disability” (or impairment - the terms often being used interchangeably). This is an “inside out” approach to disability. In the UK the un-rectified social model of disability meant “the disabling consequences of social impairments” (i.e. social barriers). This is an “outside in” approach.

The emergence of an “inside out” approach in “disability” politics is part of the cultural “dumbing down” that is now taking place in Britain (typified by Blair's balls-up: the dumb dome). This includes things like the dumbing down of television which prevents anything but trivial entertainment (and led to my **Outside, Inside Out** paper), the conversion of universities into educational factories for the production of learning materials which can be consumed by customers (rather than studied by scholars), the transformation of health and welfare professionals into technicians administering “care” according to computerised checklists, etcetera, etcetera. These are all essentials of the new “modernised Britain” and they help create a climate of mental confusion about the connection between a general decline in the quality of life at the same time social wealth increases.

The creeping stress and shallowness of life demoralises health and social welfare workers no less than disabled people facing escalating charges for the services they require. “Care” and home help staff watch the people they assist struggle to make “ends meet”, while they work for minimal pay, mostly alone and with negligible support. In these circumstances even the “children of Thatcherism” with all their avaricious outlook on life must begin to question the dumbing down that goes with “modernising social services”. The re-emergence of radicalism amongst workers, then, is on the agenda and disabled people need to look for new alliances in this direction.

However, such collaboration cannot be on the old campaigning terms which were aimed at improving the practice of existing professions. I believe that our experiences in Centres for Integrated Living and a deeper grasp of the implications revealed by the social model of disability all point to the absolute necessity of creating **new** Professions Allied to the Community (PACs). These would contrast with the fossilised Professions Allied to Medicine (PAMs). Constructing PACs is a massive task in which all disabled people can contribute. It opens up prospects for disabled people acquiring careers in our own interests, integrates our needs and perceptions within significant social structures (like Trade Unions) and encourages a new relationship between the disability grass-roots and service practitioners who want, but are unable, to challenge their oppressive practices. A BCODP annual conference which facilitated such grass-roots participation in innovative planning for our future would not have to be cancelled because of lack of participants![[9]](#endnote-9)

Oh, and the leader who was horrified when I went public with concerns about the movement; why the person now works for the Disability Rights Commission[[10]](#endnote-10) headed by our good friend and champion of the disability movement Bert Massie![[11]](#endnote-11)

1. Available [online here](https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-Inside-Out.pdf) - DPA Team [↑](#endnote-ref-1)
2. **Disability Now** was the magazine of the charity Scope (which used to be called The Spastics Society). Scope had, at best, a complicated relationship with the Disabled People’s Movement. While it was part of the **Rights Now!** coalition of organisations fighting for anti-discrimination legislation alongside disabled people’s groups; its commitment to segregated care facilities, use of patronising advertising to fundraise, and refusal to hand control over the organisation to its users made it the natural enemy of much of the Movement. The fact that Finkelstein chose to publish his critique of other disabled activists there was a profound sign of his distrust that the DPM’s national magazines and newspapers would publish his views in full. - DPA Team [↑](#endnote-ref-2)
3. Richard Wood was, at the time the article FInkelstein references was written, the Chief Executive Officer of the British Council of Disabled People (BCODP) - DPA Team [↑](#endnote-ref-3)
4. We can’t find evidence of the academic Tom Shakespeare using the word ’rectify’ in relation to the social model, but in 1992 he argued that it needed to be ’mediated’ by a greater focus on the personal experience of impairment and illness (see Shakespeare’s ’A reply to Liz Crow’ in the September 1992 issue of **Coalition** - pages 40-42). Later, Shakespeare would reject the social model entirely (See Shakespeare’s book **Disability Rights and Wrongs**, published by Routledge in 2006) - DPA Team [↑](#endnote-ref-4)
5. Regionalisation was adopted as a way of re-organising and expanding BCODP’s membership in the late 1990s as part of **The Way Forward –** BCODP's strategy after the failure to win the anti-discrimination legislation that it wanted. The basic idea of regionalisation was that BCODP employees, officers, and contractors would find groups of disabled people that were not BCODP members in regions where the organisation wasn’t represented, recruit them into BCODP, provide their leading members with specialist recruitment and organisational training, and give more basic skills training to other members. It was hoped that this would give BCODP a stable foothold across Britain, and mitigate the over-representation of groups in the South East and Midlands within the wider organisation. For details of the plan, see Sandy Marshall’s report to BCODP’s 1999 Annual General Meeting (held at the DPA). Regionalisation did not prove to be successful; while a few new Disabled People’s Organisations (DPOs) were set up through it, few survived for long, and there were not enough to make up for all the DPOs who either folded up or left BCODP in the early years of the new millennia – DPA Team [↑](#endnote-ref-5)
6. The Disability Alliance (DA) were a group of charities and academics campaigning for better benefits for disabled people. The DA split from the Disablement Income Group (DIG), a campaigning charity working on disabled people’s incomes, at around the time Finkelstein and others were forming UPIAS. The DA argued that DIG had failed to win a better income for disabled people from the government because it had not lobbied politicians hard enough when they were already under political pressure on other issues. UPIAS, on the other hand, argued that the focus on asking politicians for hand-outs, rather than building a movement of empowered disabled people who could fight on their own behalf, was the real reason DIG had become toothless; and accused the DA of using the same disempowering tactics as the group they had broken away from. For the debate between the two groups see [Fundamental Principles of Disability (1976)](https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf#:~:text=1.%20Fundamental%20principles%20to%20which%20we%20are%20both,of%20others%2C%20assume%20control%20over%20their%20own%20) - DPA Team [↑](#endnote-ref-6)
7. The Disabled People’s Direct Action Network (DAN) is a group of disabled activists who engage in disruptive protests to force social change. Their campaigns in the 1990s included chaining themselves to buses and trains to highlight the inaccessibility of public transport, and organising demonstrations at the constituency offices of politicians who voted for disablist legislation – DPA Team [↑](#endnote-ref-7)
8. While BCODP had increasingly become concerned with genetic engineering and euthanasia throughout the 1990s, these had largely been treated as questions of ’bioethics’ (ie, what doctors and other scientists should be allowed to do to pursue scientific discovery), rather than as economic or social questions. See Bill Albert’s **Disability and the New Genetics**, written as a BCODP position paper in 1999 – DPA Team [↑](#endnote-ref-8)
9. BCODP had been forced to cancel it’s national conference in 2000 due to too few people registering to make the event financially viable – DPA Team [↑](#endnote-ref-9)
10. The charity led group tasked by the government with monitoring the enforcement of the Disability Discrimination Act – DPA Team [↑](#endnote-ref-10)
11. Bert Massie (1949-2017) had a long history in disability charities in Britain – starting working for the Liverpool Association for the Disabled (sic) and then the Royal Association for Disability and Rehabilitation in the 1980s. While active in the anti-discrimination legislation campaigns of the 1980s and ’90s, Massie was seen as a conservative force in disability politics by many in the movement. He was memorably nicknamed ’the Poodle’ by Scorpio – the anonymous columnist in **Coalition** - for his willingness to go along with whatever charity bosses or central government had decided was a good idea at any given time – DPA Team [↑](#endnote-ref-11)