Alison Sheldon:

Disabling the Disabled People's Movement? The influence of Disability Studies on the struggle for liberation

Draft plenary paper for the 3rd Disability Studies Association conference, Lancaster, UK, September 18th-20th 2006

ABSTRACT: There is a long tradition of thought which questions the role of the intellectual in liberation movements – movements of workers, women, black people and so on. The influence of educational institutions and academic disciplines in the maintenance of oppression has also been widely discussed. Developed from and for the disabled people's movement, Disability Studies in the UK was built on foundations laid by activist 'organic' intellectuals and has subsequently prided itself on its strong links with the grassroots movement. The early commitment to disabled people's self-emancipation has continued into the present with a disciplinary insistence on non-oppressive research methodologies, user-involvement, accountability to the grassroots community and concrete policy outcomes. However, whilst Disability Studies has become a thriving academic discipline and has arguably never been in a stronger position, the once vibrant British disabled people's movement is now said to be 'in decline'. With the rapid expansion of Disability Studies, many of the movement's 'organic' intellectuals have been assimilated into competitive market-driven educational institutions. It may no longer be in their interests then to challenge the disabling system that provides them with professional prestige and power. Unsurprisingly perhaps, the laudable concern with praxis seldom looks beyond short-term gains and policy outcomes. Thus the systemic roots of all forms of oppression are downplayed. If the academy has in any way contributed to the, albeit partial, successes of the disabled people's movement, it must too take some responsibility for its failures and try to formulate strategies to alleviate their affects. This paper will examine if and how recent developments within academia have effectively disabled the disabled people's movement in Britain, and consider ways in which Disability Studies intellectuals might assist the struggle towards a better society for all.

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INTRODUCTION

This year's conference celebrates the 30th anniversary of the drafting of the *Fundamental Principles of Disability* by the Union of the Physically Impaired against Segregation (UPIAS). This document has been immensely important to disabled people and their allies in the UK and elsewhere. Most importantly, it suggests a re-definition of disability which we still use today, and which formed the basis for the 'big idea' of the disabled people's movement' - the social model of disability (Hasler, 1993). Here though, I want to focus on parts of the document that are less often discussed, sometimes contradictory, and which raise some difficult questions about the role of intellectuals and the usefulness of their activities.

Fundamental Principles is a critique of the work done by "expert" sociologists in the Disability Alliance - an organisation speaking on behalf of disabled people. The Alliance is criticised for concentrating solely on incomes - what the Union views as a mere symptom of disabled people's oppression, not the root cause. This kind of '"spontaneous", unthinking reaction' to a single aspect of disablement (UPIAS, 1976: 13), is said to divert attention from the real task at hand - to develop an adequate social theory of disability which will provide an understanding of how best to eliminate disability altogether. The 'so-called experts' in the Alliance (as UPIAS calls them) are criticised for serving their own interests first and foremost, and also for impoverishing the intellectual development of disabled people both by talking down to them in what the Union call 'lay terms', and by making no attempt to provide them with any education or to raise their level of social awareness.

In order to explore whether Disability Studies might be similarly 'disabling the disabled people's movement', this paper will:

- give a very brief background to the rise of Disability Studies in the UK and the proposed fall of disability activism. Then, drawing on the *Fundamental Principles* document, I want to

- briefly consider the social function of Disability Studies intellectuals

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- Then come back to the questions of 'spontaneity' and of the proposed need to raise the disabled community's level of social awareness,

In conclusion, if Disability Studies really *is* disabling the disabled people's movement, ways will be considered in which we might try and halt this process.

THE RISE OF DISABILITY STUDIES, THE FALL OF DISABILITY ACTIVISM

When *Fundamental Principles* was drafted, the academic study of disability was on the whole confined to medicine, psychology, medical sociology and so on. The last 30 years have seen the emergence of Disability Studies as a discipline in its own right - an increasingly fragmented discipline, whose originators were concerned with:

> the study of the various forces; economic, political, and cultural, that support and sustain 'disability', as defined by the disabled peoples movement, in order to generate meaningful and practical knowledge with which to further its eradication. (Barnes, 2003: 9)

Disability Studies in the UK was built on foundations laid by activist 'organic' intellectuals (of which more later) and has subsequently prided itself on its strong links with the grassroots movement, and its insistence on non-oppressive research methodologies, user-involvement, and concrete policy outcomes. However, whilst Disability Studies has become a thriving academic discipline and has arguably never been in a stronger position, the once vibrant British disabled people's movement is now frequently said to be 'in decline' (see for example Oliver and Barnes, 2006). Is this just a coincidence or can it be argued that Disability Studies is somehow 'disabling' the disabled people's movement? If the academy has in any way contributed to the, albeit partial, successes of the disabled people's movement, shouldn't it too take some responsibility for its failures?

Perhaps the disabled people's movement is floundering on the shores of its own successes. Since *Fundamental Principles* was drafted, many of the movement's demands have been (at least

partially) met; and Disability Studies academics are generally accepted to have played a role in making change happen. Whilst some disabled individuals have undoubtedly benefited from developments like the introduction of anti-discrimination legislation and direct payments for personal assistance, there is still disability. Hence, the focus on 'rights' - which once energised the movement, and academia has largely supported - is increasingly recognised as insufficient (Oliver and Barnes, 2006; Sheldon, 2005).

Furthermore, with the rapid expansion of disability studies as an academic discipline, many grassroots activists have been assimilated into bourgeois educational institutions. Perhaps then, as was suggested of feminists working in women's studies, their political energies have been, 'disciplined' (Messer-Davidow, 2002), neutralised, and diverted away from grassroots activism (Warwick and Auchmuty, 1995). Plenty of people writing within Disability Studies describe themselves as 'activists' - it's become a kind of shorthand for saying 'I'm disabled'. But does having an impairment and working in Disability Studies automatically make you an activist? Activism has largely been seen as lying not in elite institutions like universities, but in smaller grassroots organisations under the control of oppressed people. Some however conceptualise activism more broadly as *any* 'activity towards change' (Warwick and Auchmuty, 1995: 186). So can intellectual activity in the academy be a legitimate form of activism?

A NEW DISABLING PROFESSION?

Antonio Gramsci's distinction between organic and traditional intellectuals is often drawn on when discussing these kinds of questions: 'organic intellectuals' being those intellectuals who emerge organically out of every social grouping - forming a kind of intellectual vanguard for that group; and 'traditional intellectuals' being those already existing intellectuals who regard themselves as a separate and autonomous community. Hence for writers like Mike Oliver (1996: 167) - if you've got an impairment and you're part of the 'movement' it's difficult *not* to be an organic intellectual. Disabled academics then are said to be less of a threat to the disabled people's movement than traditional ones - less likely to 'sell -out', and less likely to distort the experience of oppression

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because their work is 'rooted in personal and collective experience'.

So does having an impairment confer some kind of intellectual integrity? Impairment status alone tells us little about ideological positioning, as Oliver goes on to remind us. It's what you *do and say* that's important not who you *are*. And since 'being oppressed by one system… [does not] prevent our being privileged in another, by virtue of our occupation' for example (Jackson, 1996: 53), even *disabled* disability studies intellectuals may have vested interests not in changing things significantly, but in keeping things pretty much as they are.

When discussing intellectuals, Gramsci *also* makes a useful professional/non-professional distinction. For Gramsci, doing and thinking can't be separated so there's no such thing as a non-intellectual. Everyone is an intellectual, but we do not all have the '*function* of intellectuals' (Gramsci, 1971: 9, emphasis added). There exists a *professional category* of intellectuals that has a distinct social function. Hence Disability Studies academics belong to a profession, and - as Illich *et al.* (1977) have argued - professions have a propensity to be disabling.

Disability Studies could be making a more thorough critique of the structures and institutions that sustain disability - including the institutions that pay our wages, but most of us are (perhaps understandably) concerned about our careers, and unwilling to rock any institutional boats. We benefit from disability, even the disabled people amongst us. No wonder perhaps that our stated concern with praxis seldom looks beyond short-term gains and policy outcomes - things that ameliorate the symptoms of disability whilst leaving the cause intact.

Fundamental Principles did not exactly predict the meteoric rise of Disability Studies. It *did* however predict - with some trepidation - that 'sociologists would oust the medical profession' as the dominant group in the disability field (UPIAS, 1976: 18), and it further criticises the promotion of sociology as the 'new, dominant profession in disability' (UPIAS, 1976: 20). For the UPIAS though, even sociologists can prove their worth through their work - through their theory and through their position as educators.

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"SPONTANEITY" EXCUSES ALL?

In *Fundamental Principles*, the Union is clearly influenced by Marxist-Leninist thinking, and particularly by Lenin's *What is to be done?* (first published in 1902). This influenced their thoughts about the kind of theory that is needed, and about the role of education in the struggle. Leninism is all about the development of a "scientific" understanding of society, (an approach often neglected within Disability Studies, although see Barnes, 1995 *etc* for exceptions), and this comes through very strongly in *Fundamental Principles*. The Union maintain for example that:

> Any scientist, seeking to deal effectively with a problem, knows that the cause must first be identified. Therefore, if disability is a social condition then an analysis of the ways in which society actually disabled physically impaired people is obviously required before the condition can be eliminated. (UPIAS, 1976: 13)

Lenin was not opposed to reforms - things that made people's lives more tolerable whilst leaving the inequitable system intact. He was though, very critical of those who restricted 'the aims and activities of the working class to the winning of reforms' (1970: 75) - those who encouraged 'spontaneity' alone. ('Spontaneity' in this sense denotes thought or action uninformed by 'systematic educational activity' (Gramsci, 1971: 198), reaction to the *immediate appearan*ce of oppression only). *Fundamental Principles* is equally emphatic in its opposition to 'spontaneity'. Hence one of the Union's criticisms of the Alliance concerns the fact that they are ruled by 'spontaneity' and 'have not produced an adequate social theory of disability' (UPIAS, 1976: 20) - one that makes a 'full analysis of the organisation of society' and thus 'leads to the very essence of disability' (UPIAS, 1976: 14).

Since 1976 there have been some noteworthy attempts to produce such a theory by writers including Paul Abberley (1987), Mike Oliver (1990), Brendan Gleeson (1997, 1999) and Carol Thomas (1999, 2004). Even so, according to Vic Finkelstein (2002: 13), one of the Union's surviving members, the disabled people's movement 'still awaits an explanation of the social laws that make, or transform, people with impairments into disabled people'.

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Disability Studies is largely dominated by discussions of policy, an orientation that arguably 'represents both a weakness *and a strength* of the field' (Gleeson, 1997: 181). Whilst symptomatic of the "spontaneity" to which the Union refers, it also shows a commitment to praxis - albeit a reformist praxis. Perhaps though, we need to go 'beyond ramps' (Russell, 1998) and aim for a less "spontaneous", more 'theoretically-informed praxis' - one that seeks to engage 'major theories of society' (Gleeson, 1997: 181), and, as Carol Thomas (2004) has urged, is global in scope. This might assist us in producing the social theory of disability that *Fundamental Principles* stresses we so urgently need.

EDUCATION, EDUCATION, EDUCATION…?

This will all of course all be 'academic', unless we share our thinking with those whose lives it concerns. Lenin, argued that '*all distinctions as between workers and intellectuals*, should be *effaced*' (Lenin, 1989: 174), and proposed that providing workers with a political education was a key duty of the intellectual - a duty which was not adequately met. He was not suggesting that intellectuals should talk down to the workers about things they already knew - they after all were the experts on their day-to-day lives. Rather, they should tell them more about what they *didn't* yet know, and would not learn through their personal experience - political knowledge. This would then bring the workers up to the level of intellectuals.

Similarly, the UPIAS criticise the Alliance for talking down to them and for making no attempt to educate them, 'nor to raise [their] level of social awareness'. They claim that the Alliance's 'narrow approach… impoverishes the intellectual development of disabled people in [their] own struggle', by isolating them 'from the social and ideological developments' that are going on around them (UPIAS, 1976: 16).

So rather like Lenin, (and the Black Panthers - another Lenin-inspired group - see Seale, 1991) the UPIAS seem to champion the role of an intellectual vanguard in providing the uninformed masses with a raised level of social awareness, and thus, presumably, a greater motivation to self-organise. This suggests a situation where the intellectual tail wags the ignorant dog, and as

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such is very different to the way that many others view things - Rosa Luxembourg for example was a great believer in the spontaneous activity of the masses (Bottomore, 1991), and this is generally also the case within disability studies. This orientation also sits a little uncomfortably with *Fundamental Principles'* rejection of professional expertise. So what, if anything, can we learn from this sometimes contradictory document?

CONCLUSIONS: 'WHAT IS TO BE DONE?'

UPIAS were a short-lived organisation, and with their demise there is arguably no faction of the disabled people's movement that is attempting to grapple with the same kinds of issues. Neither are they being consistently problematised within Disability Studies. The question as to whether Disability Studies is disabling the disabled people's movement, is a very complex one, but that shouldn't put us off trying to find answers. If we want to avoid Disability Studies being part of the problem, perhaps we could do worse than think about a few fundamental principles implicit in the UPIAS document. Various means are highlighted through which academics might be 'disabling' - their role as professionals, their subservience to spontaneity, and their lack of effort to provide the disabled community with a political education. These are all areas where changes could be made.

Disability Studies professionals could confront oppressive practices in their own institutions, even if this means putting their own privileged positions at risk. They could work harder at the difficult task of producing an adequate social theory of disability - a theory that does *not* examine aspects of disablement in isolation, seeks causes not symptoms, and aims to think of future generations rather then simply embracing 'spontaneity'. Finally perhaps we need to more actively share our skills, knowledge and resources with the people we purport to be representing; and try to provide the political education that might serve to raise levels of social awareness and increase the urge to collectively self-organise and demand change. Perhaps the time has come to 'return our education to the people who gave it to us' (Nyerere quoted Sivanandan, 1990: 2).

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Fundamental Principles has undoubtedly been a vitally important part of many people's political education, and without it, Disability Studies may well not have emerged in this country in quite the form it did. Disability Studies has a continuing duty to seek out new ways in which to assist the struggle towards a better society for all. If this duty is shirked, we may indeed be disabling the disabled people's movement.

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