Finkelstein reviews the development of radical British disability organizations and his own personal history and thought in their evolution. Finkelstein, a psychologist by training, was tutor in Disability Studies at the Open University and is now Visiting Senior Research Fellow in the Centre for Disability Studies, Leeds University. Finkelstein has a disability.

A PERSONAL JOURNEY INTO DISABILITY POLITICS
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In this presentation I have tried to provide a background sample of where I came from and the issues that I think we were trying to deal with at the time. I hope, too, that I can introduce you to some of the outstanding problems we face in our struggle for a social interpretation of disability.

Over the last thirty years we've come an awful long way. I think, particularly amongst some of the younger people now, that few will know the kind of difficulties we faced when disability was totally viewed as a medical problem. Anyone suggesting that maybe it was more to do with social rights was regarded as kind of bananas. So, when we look at what we have today, we should not lose sight of the awful long way we have come in this time.

A long time ago the Sunday morning Link programme started on television. It was wholly concerned with disability and was presented by Rosalie Wilkins. There were a lot of discussions before that got off the ground. I was fortunate in attending some of those discussions. At one of these consultative meetings I argued that instead of having a programme with an occupational therapist presenting aids, equipment and discussing current legislation relevant to disabled people – that sort of thing – we ought to do much more: explore the nature of disability (what its really all about). The programme ought also to look at important key issue for us – e.g. that society is disabling us and therefore it is society that has to change, not disabled people. I remember at one meeting a person who had been involved for some time in the so-called disability world, the professional world, protesting "But what you're saying is revolutionary. It'll never happen. People will never regard disability as something that is created by society. Disability is something you're born with or when you have an accident. It's part of you and people need to intervene to help you. You need professional services." So... in wanting a television programme that interpreted the nature of disability in social terms, that it's not disabled people who need to change but actually the non-disabled world that needs to change, this was called *revolutionary*! This experience impressed upon me just how challenging many non-disabled people regarded the changes that we wanted.

But there was another event that equally influenced my understanding of disability. This has to do with my personal experience in South Africa. Here's the background. I was in jail for anti-apartheid activities. This was the only time in South Africa that things were made accessible for me. In jail I was provided with a bed (political prisoners slept on a mat on the floor) and assisted with 'helpers' because, of course, the jails were otherwise totally inaccessible. *Somehow, when the state has a need it does make things accessible!* Anyway, when I was eventually released after doing *hard labour* they issued me with a five year banning order under the *Suppression of Communism Act*. A five year banning order was pretty standard at that time in South Africa and it prevented you from carrying out any activity what-so-ever which would further the struggle against apartheid. I want to list a few items from the banning order that was issued to me (summary extract from 5 year banning order – 18th January 1967 to 29th February 1972):

I was living in Johannesburg at the time and under the banning order I was prevented from leaving Johannesburg without permission; prevented from going into any African area; any premises like a factory; any premises in which any publication is prepared, printed or published; any premises of any organisation which is defined by the government (the government may define any organisation that it wishes such as for example the Leeds Coalition of Disabled People or the Manchester Coalition of Disabled People); any premises where there's a university or educational facilities except for the purposes of my masters degree; any area set aside for the occupation of coloureds or Asian and any premises in which there's a court except if I was involved. I was not allowed to communicate with any person who was named on a list under The Suppression of Communism Act. And I was not permitted to do any of the following things: prepare a publication; print a publication; give any educational instruction to anyone and take part in any activities of an organisation named by the government – e.g. if The British Council of Disabled People had been named by the government I wouldn't be allowed to take part in it.

In practice the banning order meant that for five years I couldn't do *anything*. Now, for me, what was interesting is that when I was handed the banning order, and looked at it, I thought "Well, this is not going to make much difference to my life because most of the things I'm not allowed to do I can't do anyway – they're inaccessible. All these premises, facilities and social meetings are inaccessible anyway!" It was with this experience still fresh in my mind that I came to the UK in 1968 as a refugee and met up with the emergent British disability movement.

Soon after arriving in the UK I read Nelson Mandela's statement at his SA trial:

'Africans want to be paid a living wage. Africans want to perform work which they are capable of doing, and not work which the Government declares them to be capable of. Africans want to be allowed to live where they obtain work, and not be endorsed out of an area because they were not born there. Africans want to be allowed to own land in places where they work, and not to be obliged to live in rented houses which they can never call their own. Africans want to be part of the general population, and not confined to living in their own ghettoes. African men want to have their wives and children to live with them where they work, and not be forced into an unnatural existence in men's hostels. African women want to be with their menfolk and not be left permanently widowed in the Reserves. Africans want to be allowed out after eleven o'clock at night and not to be confined to their rooms like little children. Africans want to be allowed to travel in their own country and to seek work where they want to and not where the Labour Bureau tells them to. Africans want a just share in the whole of South Africa; they want security and a stake in society.

Above all, we want equal political rights, because without them our disabilities will be permanent. I know this sounds revolutionary to the whites in this country, because the majority of voters will be Africans. This makes the white man fear democracy.'

From MANDELA, Nelson (1978) *The Struggle Is My Life.*
London, International Defence and Aid for Southern Africa.
The Rivonia Trial 1963-4. p.174-5

Well, you could say all the same things about people who have impairments. But what does it mean if you say that without 'equal political rights' identified by Nelson Mandela 'our [African] disabilities will be permanent'? Does it mean that its *not* OK if anyone is disabled by social restrictions *except* people with impairments? For us (people who have impairments) is it OK if *our* disabilities are permanent? And, if we want to remove the disablement imposed on us, why does this sound equally revolutionary to people with abilities (i.e. politicians and disability-related service providers) as it did to white South Africans? Let's

face it, disabled people face the most prevalent, world-wide, persistent, resistant to change and endemic form of apartheid, to put it mildly, of any human group throughout the world!

For me the answers to these questions emerged when I met Paul and Judy Hunt in the UK.

In the late 1960s the Disabled Income Group (DIG) in Britain became one of the largest mass organisations of disabled people in the world. It is important to appreciate this because many people seem to believe that the USA disability movement has always led the way. If you look at some American literature at that time you will find reference to how advanced Britain was. Nowadays of course people can easily forget that all emancipatory struggles involve a historical process – i.e. the leading element in the international disability movement may be found here, or in the Scandinavian countries, before the focus shifts elsewhere. DIG campaigned for a National Disability Income as of right. From its beginnings a lot of things seemed to have happened very quickly to the organisation. Although it was started by two women, Megan Duboisson and Berit Moore (Thornberry / Stueland), who were concerned about broad social rights of disabled people and the way disabled 'housewives' were ineligible for any of the current disability benefits, policy became dominated by men, including some influential male academics, and they transformed the organisation into a rather narrow parliamentary lobbying group wholly focused on 'benefits'. This transformation meant that the main thrust of the group was to lobby parliament for legislative changes. Having started as a mass organisation, concentration on parliamentary lobbying meant that the grassroots membership soon had no clear role within the organisation and membership began to decline. In order to lobby parliament only a few experts are needed who know the issues and who can present and argue them effectively. It is in this changing situation that I came to Britain and soon after my wife, Elizabeth, and I met Paul and Judy Hunt.

Paul Hunt, who had been living in residential institutions – Cheshire Homes – for most of his childhood and a considerable part of his adulthood, campaigned together with other residents for an active role in the management of the Homes. Paul made contacts around the world. He solicited literature from America and Sweden about non-institutional solutions to accessible housing, integrated education and income support schemes as well as other social concerns. He wanted DIG to take on these broader social issues. Although we came from different backgrounds our meeting was a meeting of like minds. Paul and Judy having experience of organising and mobilising disabled people, mainly within institutions, opposed all forms of discrimination and my wife and I, having supported the anti-apartheid struggle of South Africa, found that we had a common agenda – how do you change an oppressive system rather than spend fruitless time appealing to the prejudiced to cease their discrimination? We discussed the need for a new kind of organisation in Britain – an organisation that mobilised disabled people at the grass-roots level against oppression. We agreed that no single issue (such as DIG's single-minded campaign for a *national disability income*) should characterise any new disability association. It was out of these discussions that Paul wrote to the national and disability press calling for like-minded disabled people to join with him in forming a new organisation. The Union of the Physically Impaired Against Segregation (UPIAS) eventually emerged from the exchange of views circulated amongst those who wrote to Paul in response to his national appeal.

I won't go into details here why we settled on the title *Union of the Physically Impaired Against Segregation* but it is a story that needs to be told – after all we spent something like two years discussing a wide range of issues which seemed fundamental to our oppression and this was eventually expressed in the organisation's title. Of course we were also concerned with other predictable problems common to forming organisations with a campaigning agenda – whose interest comes to dominate the group's policy? We had already seen this happen in DIG – two women start a radical non-impairment-specific mass organisation with wide social objectives (surely there is significance in this) and then it is transformed into a

narrow parliamentary lobbying group dominated by the perspective of males influenced by sterile academic research. We were determined that this wouldn't happen to UPIAS. So we made sure that initially membership was only open to disabled people. This policy also drew on the American experience of the women's movement as well as the South African experience where under apartheid the oppressed (Africans) organised in the African National Congress while other racial groups supported them in separate alliances. For us, the key consensus was that the oppressed have to organise themselves, in their own interest, for the transformation of society. Of course, to transform society you've got to work with others, form alliances.

We also felt, given the background of that time where the popular concern was to campaign for a national disability income, that this, incomes approach, is basically a *compensatory* approach. What people are asking is that disabled people, because they are disabled (because through no fault of their own they are impaired), should be provided with a statutory income to compensate for their personal defects – its a compensatory approach. The UPIAS argument, however, was that the central issue is one of oppression not compensation. We don't want to be compensated for being oppressed! We want people to stop oppressing us! The logic of these different perspectives is very simple. The former interpretation of *disability* places us in a permanently dependent relationship to able-bodied society for handouts – what we called *state charity*. The latter approach says that the able-bodied society's got to change, its an oppressive society.

Not unexpected there were a range of criticisms of the new radical approach to disability. This, of course, influenced the way we set up our association and the priorities we decided for the group. Some people were also critical of who joined UPIAS – mainly people using wheelchairs. We made no effort to recruit any specific group of disabled people but insisted that members shared a common perspective. What was paramount was our focus on the need to change the disabling society rather than make us fit for society. There are, I believe, good historical reasons why people who used wheelchairs did predominate in UPIAS. They tended to be less isolated and so had greater awareness of significant social changes that were already taking place in the health and welfare services as well as political struggles and the general state of the economy. Many had been able-bodied and were familiar with social movements. On the other hand when we ask why people with cerebral palsy were so absent from self-help organisations *of* disabled people it may be that because they were born with an impairment they were often 'overprotected' by caring parents and consequently isolated from active contact with radical social movements. They tended to be more passive having been indoctrinated with the understanding that people with abilities will always look after their needs. It is, of course, nice to be continually surprised by individuals who somehow break free from the political apathy that has characterised a group with which they are identified. The visible prevalence of people using wheelchairs in UPIAS made some groups, like the deaf organisation we tried to contact, awfully suspicious of what we wanted to achieve. Their own bad experiences with people who use speech, and the difficulty caused by lack of funding for signers made it virtually impossible for us to communicate. Clearly, the history of where we are now was influenced by the kind of choices that were forced on us, the limitations of our resources and the assumptions about the meaning of disability that were prevalent at the time.

So, to summarise ... UPIAS decided that as there were already a lot of organisations that had been looking for compensatory approaches to the difficulties that we faced we had a choice: you see disability fundamentally as a personal tragedy or you see it as a form of social oppression. The times demanded that we had to put it as a clear choice between contrasts. If the central concern is 'oppression' then action for change needs to be 'emancipatory', civil rights and so on. If the central concern is that we suffer from a 'personal tragedy' then action for change needs to focus on the provision of 'care' and 'compensatory'

sources of income and so on. I think you can fiddle with these basic differences as much as you like but they are always ready to emerge into the open because this is the reality of the society in which we live.

UPIAS views about disability contrasted sharply with all established organisations *for* disabled people and the assumptions behind all service interventions as well as the objectives of many of the older organisations *of* disabled people at that, late 1960's early 1970's, period. Their approaches to disability, we argued, were promoted without any critical analysis of the nature of disability, or the nature of the oppression we faced. If disability *is only* a personal tragedy you do not have to question prevailing assumption and therefore the medical and other related professions may legitimately and unquestionably dominate interpretations of our lives. The need for a new theory about disability only seriously arose when we argued that the central issue was one of overcoming oppression.

In the beginning we naively tried to convince the established organisations, such as the Spastic Society in a meeting we had with them, that civil rights (changing the dominant social approach to disability) was a priority but we were regarded as extremists. The 'personal tragedy' view prevailed as long as they could point to the passive and dependent 'cripples' in the Spastic Society and put them on display. I once went to a school to talk to the students and naively argued the UPIAS view that disabled people could be fully integrated into society if the disabling barriers were removed. I don't think the students fully understood what I was saying (these ideas being so foreign to the cultural indoctrination they were taught regarding their own predicament), but the teacher knew the implications of the argument very well (seeing that it obviously challenged the segregated education system which maintained her career). She let me finish and then, turning to the students, said "We don't agree with him do we!" She selected one of the students adding "You don't agree do you?" And of course the child could do little but agree with the teacher.

Experiences such as this convinced us that we needed to develop and promote a radical theory or interpretation of disability. Without this we felt it would be near impossible for disabled people to challenge the traditional 'tragedy' view of disability that sustained current service provision as well as the welfare of existing organisations – there simply was no alternate interpretation which questioned the prevalent understanding of disability. To fill the gap UPIAS withdrew, in practice if not intention, from the public arena and engaged in private discussion about the meaning of disability. We spent about two or three years exchanging ideas in an internal circular, because of the practical difficulties in meeting, in which we discussed issues such as alternatives to 'residential institutions', integrated education, 'oppression', etc. I hope that one day we'll be able to get the arguments from those internal circulars into the public arena because they are still unresolved and pertinent to the issues of today.

With the decline in DIG not only UPIAS emerged but also the Disability Alliance. The latter organisation came into being when a bunch of professional 'experts' and some disabled people, who had been active in DIG, decided that the reason DIG wasn't effective in its campaign was because the argument for a national disability income wasn't sufficiently studious and their lobbying lacked the necessary prestige. What was needed, they believed, were more academics (people who were really more knowledgeable about the issues of disability than rank and file disabled people) to put a better case to government! The failure of DIG, then, found expression in two groups – one a very elitist organisation and the other, UPIAS, wanting to mobilise and get disabled people involved in their own emancipation.

That's a brief background to our promotion of the new social interpretation of disability. In the circumstances UPIAS felt obliged to produce a criticism of the Disability Alliance and the much quoted *Fundamental Principles of Disability* was published in 1975/6. In this booklet you will find the UPIAS commentary on our discussion with the Disability Alliance, which I wrote, and Paul Hunt wrote the Fundamental Principles, which provided the title of the booklet:

> 'Fundamental principles to which we are both in agreement: disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.'
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> UPIAS (1976) *The Union of the Physically Impaired Against Segregation* and *The Disability Alliance* discuss *Fundamental Principles of Disability.*

I think these principles stands up very well today. Paul Hunt also wrote the UPIAS Policy Statement – well worth looking at because it summarises the social interpretation of our situation. This is perhaps dated in places now but all the contemporary issues are still there. We produced these documents to make public our case for a complete rethinking of disability. At that time we talked about developing a *theory* for the social interpretation of disability. Mike Oliver, being a sociologist, elaborated the UPIAS view and produced a detailed argument for the social model of disability. In this form the social interpretation of disability was widely disseminated and discussed. Sadly a lot of people have come to think of the social model of disability as if it were an explanation, definition or theory and many people use the model in a rather sterile formalistic way.

Around this time, as we developed our ideas about disability, the book by Miller and Gwynne (Miller, E.J. and Gwynne, G.V. 1972 *A Life Apart*. London, Tavistock Publications) began to circulate more widely. This, as many will know (since it has been frequently criticised as perhaps the epitome of entrenched bigotry), looked at residential homes for disabled people. Paul Hunt had been involved in their invitation to Le Court, the Cheshire Home where he stayed, because at the time the residents were trying to participate in the running of the 'home' despite the administration's resistance. They fully expected social science research would confirm that the welfare of an institution could be enhanced by engaging its residents in the management structure. To their horror Miller and Gwynne concluded that as the function of residential institutions was to maintain disabled people who were 'socially dead' until actual death this should be done under 'horticultural' rather than a 'warehousing' stewardship. The residents felt, of course, that they were badly let down by social science research and the anti-science sentiment, often expressed by disabled people, was reinforced.

Coming so recently from apartheid South Africa, and having felt that my 'banning orders' did little more than confirm the prevailing restrictions already imposed on disabled people, I couldn't help but conclude that 'social death' aptly expressed the status of disabled people in society as a whole – we are virtually invisible in the media (television, newspapers and magazines); social and environmental barriers prevent us from playing an active role in society (particularly those who have been incarcerated in institutions); we have no serious influence on government (compared to service providers with abilities who 'care' for us); we are all too depend on 'state charity' as a source of income; and so on... you couldn't describe our reality better than to say we're 'socially dead'. This is apartheid on a grand scale!

The issue seemed not so much whether we are or are not 'socially dead', but what we can do about it? Like South Africans under apartheid it is not a matter of research or debate whether we are socially dead (whether our 'disabilities will be permanent' in Nelson Mandela's memorable phrase) but what to do about oppression. What is the route to emancipation? You can, as the saying goes, 'stand on your head' trying to convince people who make you socially dead to change their ways but 'you ain't going to get nowhere'. In all these years since Miller and Gwynne were approached to assist with emancipating research institutionalised residents still have little control over their lives. The reality is that we have to find new answers for our emancipation otherwise people with abilities only have the imagination to come up with suggestions for taking 'care' of us, processing our 'social death' in a humane way or, in the final analysis, providing euthanasia.

For me the critical issue is how can disabled people have a meaningful, if not revolutionary, impact on the disabling society? Clearly, as long as we remain 'socially dead' we are unable to engrave our signature into the fabric of society – in particular those material aspects of social relations which render our 'disabilities permanent'. In my opinion while it is true that our organisations have had some influence in the campaign for civil rights many of these rights (charters, mission statements, etc.) are in any case part of the need to regulate excesses of the market economy. 'Globalisation' has increasingly forced personal 'earned income' to be dependent upon employee collaboration for greater productive efficiency. This is set at the highest level by how much people with abilities can tolerate in the labour market before they either breakdown or rebel. Rebellion produces concessions in the form of rights and charters. However, this frenetic pace of toil makes it impossible for disabled people to gain acceptance for our more humane pace of work. In this context only charity, civil rights legislation, and state charity (benefits) stands in the way of disabled people en masse becoming beggars on the streets. On the other hand the people who *do* have an influence on government etc., are the people who work in the disability 'industry'; care managers, social workers, occupational therapists and doctors, etc. They present a catalogue of assumptions about our inadequacies which are perfectly compatible with the agenda for social organisation set by parliamentarians with abilities. As long as our influence is not structurally rooted in the health and welfare sectors of society we cannot expect to have a real impact on society in our own terms – i.e. we will remain 'socially dead'.

My view, then, is that the only way we can gain real influence is by finding a means of entering the health and welfare labour market *in our own terms* – i.e. by developing our *own* profession. In addition to arguments dictated to us by the nature of the market economy there are a number of reasons why this call for our own profession has reached its time: we now have more than sufficient research on the inadequacies of the health and welfare professions (*Professions Allied to Medicine*: PAMs) in relation to disablement for a convincing case to be made about their intrinsic inability to meet our personal and social needs; *Disability Studies* has been firmly established and the quality of the courses presented not only demonstrates the ability of disabled people to interpret our own situation at a higher level than hitherto attained in traditional academic courses but, more significantly, has established a solid intellectual foundation for the development of a professional qualification; and finally, we now have enough practical experience setting up and running services for disabled people in Centres for Independent or Integrated Living (CILs) to clarify what skills are needed for service provision. This means that many of the elements for us to go to the next stage and begin developing our own profession from our own perspective have already matured. All that remains is for us to fire the imagination of the disability movement in supporting the venture, expanding our personal confidence in the emergence of disability culture within which to locate such a profession, and the academic will for curriculum development critical of 'compensatory' approaches to disability-related service development.

Compensatory 'care', benefits and equipment are provided to enable our access into the able-bodied social and physical environment. This is contrasted with an approach to intervention which introduces our perspectives and culture into the structures of society so that provision is made more accountable to a multi-cultural population. The contemporary professions (PAMs) work within the compensatory care framework. What we really need, however, is to create a *Profession Allied to the Community* (PAC) – i.e. designated community workers who are allied to particular groups that are disadvantaged by the way that the social and physical environment is constructed around the dominant values. I think the creation of such a profession is the *central challenge* that disabled people face today. In my view there are now a number of factors in our favour for beginning this undertaking. One such factor is the collapsing health service. The unravelling of the National Health Service (in reality a National Medical Service) has provided us with a window of opportunity to intervene in restructuring service provision. Exactly how we are to do this is the challenge that should occupy our critical faculties. That means a better grounding in disability

theory is needed – in particular a theory which adequately covers the distinction between 'impairment' and 'disability'.

These terms have always been confused and from its early days an issue UPIAS regarded very important to disentangle. A compensatory approach makes no distinction between the two terms precisely because the confusion maintains the traditional focus on the 'defective' individual whose deficiencies are then said to *cause* social disadvantages. Since such disadvantages are no fault of its own a 'caring' society, the argument goes, will humanely concede 'rights' and provide compensatory services and benefits. This not only frees people with abilities from *all* responsibility for our predicament but the compensatory approach encourages a feel good-factor for being charitable. A complete inversion of social reality! Indeed this illusion about what are in practice 'compensatory' civil rights being a big idea is so enchanting that even the disability movement has been captivated (much to the delight of politicians with abilities) into believing that civil rights can provide a platform for announcing our commitment to emancipation.

In this respect I would recommend the book by Marta Russel (Beyond ramps: Disability at the end of the Social Contract, 1998) which debunks 'civil rights' as a rather simplistic solution to our emancipation.

Clearly there is a link between having an impairment and being a disabled person. Having an impairment is a prerequisite for being a disabled person but having an impairment cannot *cause* a person to become disabled. Even losing an arm and an eye does not *make* a disabled person. The national culture would have to attribute certain characteristics to such impairments before designating the person as being disabled. Once these attributes are embedded in the national culture, and accepted as defining features of disability, then impairments such as missing an arm and eye would not only formally become disabilities but they would be seen as the *dominant* characteristics of the individual (i.e. the person would be 'labelled disabled'). In such a society acquiring certain culturally identifiable impairments transforms the individual at the same time into a person with a disability. Both 'impairment' and 'disability', then, become attributes located within the individual. Thereafter the two conditions can be awfully difficult to disentangle.

By way of example we might wonder at the prominent celebration of a person with major impairments in a public arena. The rule, after all, is surely to hide disabled people away! Standing proudly on his column in London's Trafalgar Square the statue of Horatio Nelson defies modern infatuation with physical perfection by flouting his impairments. How is this possible? The answer, surely when we refer to the insight provided by the social model of disability, is that Admiral Nelson was *not* a disabled person despite his arm and eye impairments. In his time the disabling barriers he faced were overcome to ensure that he could function as a vice admiral. Nowadays, of course, he would be disabled and there would be no public statue because modern British culture says disabled people can't be on active service in the armed forces!

USA President Franklin Delano Roosevelt was, of course, like Admiral Nelson, *not* disabled despite using a wheelchair because all barriers to his Presidency were removed. On the other hand, unlike Admiral Nelson, he was born into a modern culture where having an 'impairment' is supposed to directly 'disable' a person; so much so that 'impairment' and 'disability' are invariably seen as synonymous personal attributes. In this culture where body perfection is an obsession a public statue of President Roosevelt shouldn't show him sitting in a wheelchair because *a person with a disability* is inconsistent with the social status afforded by the presidential office. Quite simply his presidency subverts the assumed correlation between having an impairment and being disabled (a person with disability). The only thing to do was emphasise that he was not a person with a disability by *hiding* evidence of what otherwise would be a *dominant* characteristic – the impairment. So now we are presented with a statue to a major USA public figure that takes care to hide any evidence of his impairment.

If, in their cultures, neither Admiral Nelson nor President Roosevelt were dysfunctional and therefore they were not disabled (people with disabilities) despite their major impairments this makes nonsense of the historical lists of disabled people which are constructed by only using evidence of an individual's impairment. I don't believe disabled people can reclaim our history by falsifying cultural reality and seeing a causal connection between impairment and disability.

Since there is no *causal* connection between 'impairment' and 'disability' we, nevertheless, still need to explain in what way their attributes are related. That there is a link cannot be doubted but if they are not causally connected then there must be a hitherto unrecognised intervening variable. Can the social model of disability throw any light on this? To do this we would need to identify a variable external to the individual and located in the composition of the disabling society. Such a global factor common to the majority population, I hope I have demonstrated, can be found in the national culture *at a particular historical period*. In our time the collapsing British health and social services is leading to statutory 'care' being increasingly replaced with 'care' in community governed by 'rights', with the recipients of assistance expected to contribute financially. While this is a significant cultural change the continuing adherence to 'care' gets us nowhere nearer to what can be called an emancipatory culture. In my view we need far greater theoretical clarity, backed up with rigorous research, to reveal the role played by the national (i.e. dominant) culture in underpinning the *disabling* consequences of social *impairments*. Unless we do this we will not break the link between impairment and disability – in Nelson Mandela's sense of the term, our disabilities will be permanent.

Questions and Responses

The following questions were sent prior to the presentation. Most of the questions were covered during the talk and at the end of the presentation a response was given to a selection of queries. In the time available it was not possible to respond to any in detail.

In my view the basic issues raised by the choice between compensatory and emancipatory approaches to the dilemmas we face living in a disabling society still predominate. They have not been resolved and people still need to work through the problems we face making choices between compensatory and emancipatory answers. I do feel that we have come a long way in figuring out what needs to be done for our emancipation. The disability movement and disabled academics, however, are in a much better position to explore solutions in greater depth now. All that we have done up to now is lay the foundation for a prolonged emancipatory struggle, dig away a bit at the conceptual muddle between impairment and disability, and tried to unravel some of the mystery of why we are treated by able-bodied society as if we are 'socially dead'. I don't think we got that far travelling down what I expect will be a longer road than many people imagine. I do hope and believe, however, that the sacrifices made in the 1960s and '70s have provided the new generation of disabled people and academics with some momentum on this road.

Question:

> Some disabled people who consider themselves to be radical are self-organising into impairment-specific groups, on the basis that their identity is more strongly based with others of the same impairment. They claim the social model of disability only applies to 'an elite of mainly wheelchair users'. Do you think self-organisation on the basis of impairment is problematic? And is there any justification in taking this perspective of the social model?

Response:

This is not a new issue. It existed as a problem right from the beginning of the new era in organisations *of* disabled people. We did not *oppose* people organising in different groups. In reality it hadn't been possible, as I have already explained for example, for people who had mobility impairments and people who had hearing impairments getting together in a single organisation. But having said that what is also

needed in our emancipatory struggle, it seems to me, is some way to bring together people with different impairments into a single body organised at an overarching level. So, what was critical was the formation of a national co-ordinating body. That is why the establishment of the *British Council of Disabled People* (BCODP) was historically so important. This enables people and organisations to participate in the emancipatory struggle at different levels. In the end I believe we need to share key questions and set common goals. For e.g. it is only when there is agreement that disabled people are oppressed – whether language oppressed or mobility oppressed – that we can unite on a common ground for a non-disabling society.

I don't think there's any intrinsic conflict with the social model, or social interpretation of disability, in this approach to addressing 'the general' and 'the particular' in our movement. The *Spinal Injuries Association* (SIA) and the *National Federation of the Blind* (NFB), we should not forget, were founding members of BCODP. In my view juvenile criticisms of the social model of disability arise because it is frequently used as if it *explains* our situation rather than as a tool for gaining insight into the way society disables us. I think an awful lot of people have not spent time in understanding the social model. Its worth remembering that models are not explanations. Its like putting a model aeroplane together and placing it into a wind tunnel to gain insight into how it functions under different conditions. The model will not explain how an aeroplane flies. The social model does not explain what disability is. For an explanation we would need a social theory of disability.

There is always a danger of fragmenting organisations ending up having less impact on both the general and specific had they remained united. For us this inevitably means returning to structures more in tune with the medical than the social model. The question of what is an appropriate organisation is not so much answered by accepting the 'identities' imposed on us by the able-bodied society (i.e. a *reactive* inside-out approach) but rather by figuring out the best vehicles for impacting on society (i.e. a *proactive* outside-in approach).

Question:

> The UPIAS document of 1976 mentions the need to challenge the exclusion of people with 'physical impairments' and 'other groups'. 25 years on from this document, how far do you think disability politics has been in tackling the exclusion of these 'other groups'?

Response:

I don't think we have made any progress here. In my view disabled people have been so oppressed that there isn't any question of forming alliances with other groups until we ourselves have been able to move to some significant extent out of the ghetto into which we've been placed. We cannot expect disabled people as a group, who are still struggling with how we should interpret disability, to start forming alliances. We would quite simply, if this was attempted at the wrong time before we were ready, just get overwhelmed. I would argue that if, and when, we are able to get our own community based profession established then we would find natural allies who welcome, and want to share, such a service because it would be more relevant to their needs than can be provided by traditional professions. This would facilitate an 'alliance of equals' enabling an exchange of views and service ideas without any group predominating.

I believe that other 'disadvantaged' groups reliant on health and welfare services actually face the same kind of apartheid issues that disabled people face. Because of the similarity in community related problems I cannot imagine not linking up with other groups if we took the lead in supporting a profession allied to the community. My view is that our way forward in the health and welfare sector can pretty well only be really advanced by disabled people taking such an initiative. We are one of the groups most oppressed by the health and welfare system and, with the nationalised health and welfare system collapsing, we are in the best position to say what is the alternative. That would put disabled people in a leading role for

constructive social change – a complete reversal of expectations about disabled people. I think this is the way forward.

Question:

> In the 1980s you wrote about the potential of technology for disabled people's inclusion in mainstream society. Given that the disability movement has done much to bring disabled people's issues to public attention over the last 21 years, how do you view the usefulness of technology over that same period?

Response:

This is an area that I think warrants far greater research.

When I was involved with the Disabled People's International, the representative body of disabled people from all over the world, I was struck by the similarity of criticisms being made by everyone that we were making here in Britain about social exclusion and service provision. The proliferation of like-minded organisations was clearly not arising simply because of influence from one country to another. In general the growth has been indigenous and spontaneous. As a spontaneous international movement, then, there must be something external to the national disability organisations – i.e. the common disability experience – which is triggering this growth. This phenomena, I think, raises fundamental research issues.

I would speculate that the historical change that made this possible is the advance in technology and access to it in the growing international market. I believe the new technologies have made it possible for disabled people to fully integrate into society. Technology, of course, can be used both to our advantage or disadvantage. Advances in technology, for example, can enable surgery to make disabled people look more and more like people with abilities adding pressure on us to conform to 'normal' standards. On the other hand new developments can provide accessible transport putting pressure on people with abilities to adjust their views about 'normality'.

I think there are parallels between the radical impact of the modern electronic revolution and the changes to disabled people brought about by the industrial revolution. The industrial revolution, you will recall, was stimulated by the steam engine providing motor power. This meant that an engine could replace human, or animal, strength during the processes of food production and commodity manufacture. Physical attributes relating to strength, then, became less significant than dexterity in handling the controls which operate an engine or manipulating a mechanism driven by an engine. This is why factory workers were called the hands. While this new source of power might have been another step on the road to enabling less robust people participate in social production, in practice it led to the greater isolation of disabled people. This was because steam engines drove machines which were designed for an 'average' ('normal') worker and were housed in inaccessible factories. Increasing emphasis on normality and inaccessibility to the means of a livelihood transformed the social situation of disabled people. Although less fit people could now work, underlining the principle that 'survival of the fittest' has no meaning in human development, what is paramount to the history of disabled people is that the way production and social relations are organised profoundly affects the meaning of disability and prejudice towards disabled people.

The advent of electrically driven engines brought motive power into the home and workplace making labour saving devices much more accessible to 'non-standard' people. While this facilitated more disabled people earning a living, particularly in office jobs, it is, I would maintain, the electronic revolution which has the potential to reverse the social isolation brought about by the industrial revolution. Sophisticated electronic devices enable even the most severely impaired people operate environmental control and manufacturing systems. This has increased the possibility of disabled people entering gainful employment and independent living, but more importantly the new technology has had a radical impact on the very meaning of disability. I think this changing meaning made it easier for civil rights legislation to include disabled people.

I would speculate that disability rights legislation owes more to the way contemporary technology brought the need for independent consumer rights in the expanding global market than the disability movement would like to believe. If our full integration is now technically possible then all the compensatory 'care' professions have passed their 'use-by' date. This raises a set of new dynamics in the design and establishment of disability-related services.

Question:

> How do you respond to recent feminist and / or post-modern revisions of the social model?

Response:

Emancipatory movements are usually started by people on the political left but as the newborn movement manages to fumble its way through the first muddy barriers, not without casualties, individuals to the centre and right of the political spectrum all too often 'discover' the movement's message and claim it for their own. With success, even if small, comes reluctant recognition from the social and political 'establishment'. This precarious layer of respectability provides the new 'right-on' sympathisers with an opportunity to support the movement's objectives without its radical underpinnings. The new 'centre' and 'right' public advocates, however, invariably bring pressure on the movement's radical content to be 'rectified'. During the growth of the disabled people's movement when it was vulnerable to attack from established organisations *for* people with disabilities a united public face was needed. In this period liberal and right wing views can be presented as if these are the unified views of the movement without public challenge from the left. After some consolidation in the legitimacy of our newfound social identity, however, unity which entails censorship of 'revolutionary' views cannot be sustained in an emancipatory movement. To suppress the *left's* views would be to remove the radical content of the disability movement and reduce the emancipatory struggle to 'parliamentary lobbying', an ineffectual way of organising as we should have learnt so well from the lessons of DIG.

The question, then, in responding to feminist attempts to rectify the social model of disability is: which 'revisions' are we talking about – those proposed by the political left or right? This is not the place to make a criticism of centre and right feminists who make global claims about representing their movement. All that needs to be said, recognising the importance of personal experience, is ask what these individuals now enfeebling the social model were doing when the social interpretation of disability was advanced in the teeth of establishment opposition? How come their complaints about the restrictions they faced at the time got no further than the personal while at the same time people on the left began building an organisation adequate for a social response? Lets face it: there would be no uniquely British interpretation of the disabling society had the proposals for a rectified social model of disability underpinned the early establishment of our movement. We should remember that in the USA the social model of disability means 'the social consequences of having a disability' (or the experiences of people with disabilities facing social restrictions). 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. the oppression resulting from social barriers). This is an 'outside in' approach.

During the latter stages of the inaugural period when the disability movement was weak, the centre and right gained authority to speak for the movement as a whole and right wing feminists too came to dominate what feminism has to say about 'disability'. But there are feminists on the left and I think the time has arrived for their views to get an unrestricted airing. As long as 'what is personally good for me is politically correct for you' is allowed to go unchallenged the elite will not only provide the dominant feminist perspective, but continue furthering their careers (nowadays frequently in academic and research settings) while disabled women see little improvement in their global situation.

At a personal level I have to say that it is an unsustainable tactic of some disabled feminists to complain privately to me about other well-known disabled feminists while in public they remain silent. I think that the left perspective, particularly with the collapsing health and welfare system, needs to come out into the open much more and present its socialist agenda.

Question:

What place do you think there is for personal accounts of disabled people in disability studies?

Response:

If the central issue in the struggle for emancipation is about how to change society, then personal accounts need to be seen in this context – how do such accounts enable the individual participate in the emancipatory process. When personal accounts and writing biographies simply remain a platform for people to talk about themselves they tend to go no further than serve personal careers. This is an individualistic exercise, often elitist in nature, furthering their public image. On the other hand, personal accounts which inspire others to engage in social activities which would otherwise be too daunting do serve an emancipatory agenda.

One of the most influential personal accounts I read while working against *apartheid* in South Africa was: Julius Fuchik (1948) *Notes From The Gallows*. NY: New Century (a communist Czech's fight against German fascists; written and smuggled out from a Gestapo prison in Prague where he was killed). To me this exemplifies all that is best in personal accounts.

In UPIAS some of us argued that *personal change* is important to enable participation in the struggle for emancipation but this needs to be distinguished from *social change*. Two different concerns are involved which need linking. The dialectic relation between these different concerns means that if you're not personally developed you won't participate in the social struggle, but if you concentrate on the personal side you will never get round to participating either. The emphasis is on personal development in the context of social requirements, otherwise personal development remains at the 'what is personally good for me is politically correct for you' level.

I do hope that this personal presentation exactly illustrates how I see the personal story relate to the social struggle.

Question:

How can disabled people in the majority world overcome environmental limitations with scarcity of resources? In this situation who should play a vital role for improvement of quality of life of disabled people in the majority world?

Response:

I think it very important not to underestimate how advanced some of the organisations of disabled people are in the majority world and their capacity to find indigenous solutions to the problems that they face. In their perception of the need to transform the disabling society some of them are more developed in their thinking than found in North America or Europe, where the psychology of 'charity' often predominates and maintains the dependency of disabled people on people with abilities. We know there are examples in the majority world where disabled people have set up and run what are in practice CILs. In these centres they effectively provide a service replacing the absence of professional workers that still seem to obsess us. Of course many disabled people and service providers in the majority world do believe that the only 'modern' way to provide 'care' is the very system which many of us in the minority world would prefer to see dismantled. One of the worst examples of this was the expensive ill-conceived rehabilitation centre for war veterans built in Zimbabwe.

Having said this it would be completely unrealistic to deny the "scarcity of resources" and upsetting deprivation that can face disabled people in the majority world. I was horrified to see the effects of war in Mozambique where disabled people could end up literally with nothing. Obviously in such circumstances medical intervention and basic necessities are the priorities and only after these have been addressed is it possible to start thinking seriously in practical terms about the "environmental limitations". In my experience it is not possible to give a global response to the vastly different situation facing disabled people in majority world countries. Answers do require direct contact with each situation and engaging disabled people in a dialogue about priorities and solutions. I think that it is only through direct contact that a hierarchy of resource needs can be constructed. I am, however, adamant about the need to engage disabled people in the processes of constructing priorities for intervention as well as countering illusions about the 'care' and 'rehabilitation' solutions being exported from the minority world by NGOs and government funded aid programmes.

I think the more we become familiar with disability-related activities in different countries the more we discover that there's an awful lot of things going on which we in the developed world should also learn about. This means we ought to be encouraging international networks of disabled people whereby organisations of disabled people can do a great deal more to assist each other.

Question:

> What role do you see for academics in the development of interpretations of disability? Is the academic's position a difficult one?

Response:

I will try to answer this with a reference to my South African experience. The only places in apartheid South Africa that you could legitimately get access to literature that dealt with oppression, including Marxist literature, were in the universities. This 'revolutionary' literature needed to be made available because they had to educate lawyers about Marxism in order to prosecute people under the Suppression of Communism act. The state propaganda machine (radio, television and newspapers, etc.) needed informed personnel and they had to have some knowledge of the 'banned' literature. The only place you could get approved access to this information was in educational institutions of higher learning. OK, this is a bit of distortion but the point I am making is that one of the most important sources of information concerning oppression and the way people have responded to this is the academic institution. This is why having 'tenured' academics was so important – it enables free speech and reduces the fear of state intervention (which is why the modern decline in British tenured academic posts is so worrying).

From our point of view, people who are resticted in their access to social life (people who are socially dead), being knowledgeable about our situation, understanding constraints of the national economy and the effects of the global market etc., are all relevant to our eventual emancipation, but inaccessible to us. I see at least one of the academic's role is to make this knowledge both available and disseminated in an eductionally accessible form. Educating students who go out into the field carrying the otherwise unavailable knowledge with them also contributes greatly to the general enlightenment of oppressed groups. In this role migrating students and academics can assist ill-informed disabled people gain insight into their real predicament and rights. I would dearly love to see acadmics run free community education programmes for disabled people. Such (clandestine) programmes were run all over SA whenever radical academics had the opportunity. There are far too many seminars, workshops and conferences by academics for academics, and far too few educational innovations with the 'grass-roots' in my opinion.

I don't think university academics can lead an emancipatory movement by promoting themselves as the sole developers of disability interpretations but I do feel they can have a positive influence and feed the hunger for knowledge that accompanies struggles against oppression. This requires a healthy link between

academics, campaigners and disability organisations. In many ways we really have been quite unique in making such a connection in the UK. One of my personal joys is that I was able to forge such links when working as an academic. As long as academics are able to maintain this kind of connection I think that it can be constructive for both. The danger is that as British university courses become increasingly 'market led' rather than 'market responsive' the relationship between academics and oppressed people will be parasitic. This is the central reason why I left the academic world.

Research and referenced publications, of course, are important tools in emancipatory struggles and I do not need to mention the role played by the Leeds University Centre for Disability Studies in contributing here.

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