

**DISABILITY STUDIES:
PUTTING THEORY INTO PRACTICE**

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'Phase 3: Conceptualising New Services'

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MOVING ON

Race Studies, Gender Studies and Disability Studies in the UK all emerged within a short period of time during the latter half of the last century. Voices from each of these groups expressed growing exasperation with the way our lifestyles are understood and studied. There was increasing discomfort with the social status that the prevailing culture assigned to us and we were no longer willing to remain passive within this status. Public utilities and services, and health and welfare services were criticised for being unresponsive to our *particular* needs and the knowledge base underlying provision in these areas was increasingly questioned. Aspects of professional practice generated anger and their supporting assumptions about us were often disapproved.

Clearly one thing held in common is the change in focus, away from the attribution of all-embracing flaws within individuals, and instead turning attention onto the oppressive forces in society that disadvantage people in gaining *appropriate* access to public utilities and services. This meant defying prevailing wisdom that *individuals* are at fault and instead attributing the defining cause of the social disadvantage to the racist, sexist and disabling features of society. The development of each of these areas, race, gender and disability, followed its own particular dynamic of the time. In the 1960s the emergent shift

in the general social awareness of oppressed groups inspired disabled people to reflect on their own situation.

For us this required no less than a revolutionary reorientation – one that meant getting away from trying to make us fit for society and instead aimed at making society fit for us.

I can illustrate what I mean with an example: At that time the department of employment, I believe, mounted a campaign to encourage greater employment of disabled people. They produced a poster series depicting disabled people in various work situations each with the title “Fit for work”. We captured the new, assertive, way of thinking by rewording the title so that it would now read “Make work fit for disabled people”.

This, of course, requires the removal of *social barriers* which restrict the *particular* lifestyles of people with *impairments*: ‘social barriers’ being understood as far more than merely physical, or environmental, barriers. Despite this reorientation being in the air, change did not, and could not, occur overnight. I am talking about an unfolding awakening in the consciousness of an oppressed group which has faced perhaps the longest and most entrenched of all the prejudices held by ‘people with capabilities’. This is a prejudice which enables people with capabilities to see themselves as the quintessence of all that it means to be a ‘person’, to be ‘normal’, while at the same time identifying all other people by their possession of some aberration or other. Disabled people can’t just be people – we have to be ‘people with disabilities’, and in adopting this label for ourselves we inevitably accept the ‘stigma’ imposed on us by people with capabilities.

Paul Hunt captured the mood which directly challenged this prejudice in his pioneering 1966 book:

‘In my experience even the most severely disabled people retain an ineradicable conviction that they are still fully human in all that is ultimately necessary.’

HUNT, Paul (1966) *A Critical Condition*.
In Hunt, Paul (ed.) (1966) *Stigma: The Experience of Disability*. London, Geoffrey Chapman.

But how to project such a robust way of thinking into the disabled community? How to galvanise action so that people can engage in their own emancipation in the face of entrenched and debilitating indoctrination? How to challenge the apathy and dependency cultivated by caring services run by people with capabilities? These were the challenges that disabled people faced in the middle 1960s and early '70s when the first wave of popular action moved into a cul-de-sac and ran out of energy.

As every activist pursuing radical social change knows there is no single effective response to social oppression. Every emancipatory struggle involves action at many levels and within different spheres of life. In this paper, however, my focus is on the potential emancipatory contribution of *disability studies*. To highlight my argument I need to look at the way the first course in disability studies emerged in the UK.

The way I see it, events in the *Disablement Income Group* (DIG) and in the *Le Court Cheshire Home* made a specific contribution to the emergence of disability studies. I believe that an examination of this background reveals some features which can help us understand why disability studies was needed, what were its major concerns and, more importantly, its potential contribution to our emancipation.

OUT AND ABOUT

As long as people with capabilities regarded themselves as the standard of 'normality' and all others dependent upon them for social legitimacy, there could be no prospect of academic courses concerned with 'disability' other than medical. In practice, when living in the community was considered feasible for those with significant impairments, this meant making us as 'normal' as possible (meaning as much like people with capabilities as possible) and this approach fell under the medical branch of rehabilitation. Here, social barriers might be

considered, but always under medical direction and seen through medical glasses. The obvious limitation of medicalising social problems from rehabilitation centres, especially in the non-industrialised (majority) countries led to a version migrating into the community as 'Community Based Rehabilitation' (CBR). In reality this is merely a way of extending medical control into every conceivable level of disabled people's lives.

It should not be forgotten, too, that as the concept of 'rehabilitation' gained increasing recognition there was a proposal to set up comprehensive 'district rehabilitation services' throughout the UK with professional teams each led by a rehabilitation consultant with capabilities. Purpose built centres were also envisaged and had this materialised with full government backing and funding it would have made the development of non-medical courses in disability studies even less likely and rendered Centres for Integrated/Independent Living (CILs) near impossible to set up. The costs of such a comprehensive nationwide rehabilitation service, of course, would have been horrendous and thankfully there never was any real prospect of such an elaborate scheme being implemented.

In my view there were two interrelated influences arising from the activities of disabled people, in the '60s, which gained particular significance in stimulating the emergence of disability studies in the particular form that occurred.

In the community: The majority of disabled people lived at home in the community (albeit as invisible dependents on people with capabilities), and they were neither unaffected by the emancipatory struggles in race and gender nor completely unaware of developments in technology which enables greater control over the 'lived' environment. In general this group can be regarded as including the less severely impaired disabled people and it is, perhaps, not an accident that trendsetters channelled agitation towards the lack of financial resources to

buy-in a reasonable lifestyle. The embodiment of this aspiration was found in the '*Disablement Income Group*' (DIG) and the **overarching concern** was '*integration*', which was frequently confused and interpreted as meaning '*assimilation*' (this is why the word '*inclusion*' has come into fashion).

That '*integration*' is still a living issue is amply demonstrated every day by the almost total '*exclusion*' of disabled people's lifestyles and concerns from the vast body of journals, newspapers and radio and television programming. This has been exacerbated by the growing tendency for television and journals to focus on the lifestyles of people with capabilities who are active in the media (the so-called '*celebrities*'). Since the media is already distanced from disabled people's everyday lives, '*the media on the media*' focuses on a narrow area of social life where there are no discernible disabled people. This has been more effective in obliterating disabled people from society than euthanasia could ever hope to achieve – this is what I call '*artistic euthanasia*'!

In institutional residences: Although accommodating a minority of the disabled population a very large group of occupants were labelled '*learning disabled*' and '*psychiatric*' patients. This is where the more severely impaired disabled people were '*dumped*' and, whenever possible, this is where an insatiable search for an escape into the community was to be found amongst individuals. For the most part, inhibited from finding an organisational home for their aspirations, their **overarching concern** about appropriate '*support systems*' to enable integration in the community, had to be articulated by individuals. In this context I believe the meaning of '*integration*' was rarely confused with '*assimilation*'.

These two overarching concerns provided, I believe, a significant component of the provocation that eventually led to the presentation of learning materials in disability studies by the Open University (OU) in 1975. The critical factor was the

presence of one person at the right place at the right time who seized the opportunity that inadvertently came her way – I am referring to a non-disabled person, Vida Carver at the Open University.

I'll follow the two 'overarching concerns' separately and then argue they came together in a unique approach to disability studies at the OU.

BUYING EMANCIPATION

In the late 1960s the *Disabled Income Group* (DIG) in Britain became one of the leading mass organisations of disabled people in the world. It is important to appreciate this because nowadays people are frequently taught that the USA disability rights movement pioneered modern disabled people's social campaigns. In fact, as far as I know, in the 1960-70s the Scandinavian countries were the pioneers and during the early stages of our development in the UK they were an inspiration for us, especially in their approach to integrated education.

The Nordic countries' approach to 'integrated education' was an important reference point for us in the emergent disability movement in the 1960-70s. Elizabeth Anderson, a researcher with capabilities at the London University Institute of Education, introduced much of their work into her publications. During his enquiries into all aspects of 'integration' Paul Hunt made contact with Miss Anderson. His aim was to bring examples of integration into the UK whenever possible. Paul and I met Elizabeth and tried to convince her that research would be more fruitful if it were committed to finding ways of 'solving' problems in integrating disabled people (i.e. 'emancipatory' in contemporary terms) rather than merely investigating examples of what could be done. Sadly, she was adamant that research had to be 'objective' (i.e. 'neutral') and no further discussion was possible between us.

In the British context where benefits were available for workers who sustained industrial injuries but neglected those who had not been employed, it was, perhaps, no accident that DIG was founded by two women, Megan Duboisson and Berit Moore (alias Thornberry / Stueland). They were concerned about the welfare of the unemployed, especially disabled women who were particularly disadvantaged in gaining access to the benefits system. As a 'pressure' group the main work of the organisation was to lobby parliament for legislative changes. DIG campaigned for a National Disability Income to *compensate for disability* 'as of right'.

The emergence of DIG was an early symptom of the shifting focus away from our 'defective' bodies, which we had been conditioned into believing was the sum total of our misfortune, and onto the provision of benefits to enable a more equitable lifestyle in the community regardless of type of impairment or where this was acquired. DIG argued that with sufficient income disabled people could be *integrated* into society. Writing in the *Liverpool Association for the Disabled* publication Mary Greaves (a leading figure in DIG), presented their argument most forcefully in public:

"We who are disabled all talk long and glibly about 'integration' and 'segregation'. Many of us are not quite clear what we mean – I certainly don't – at least all the time! ... First let me be quite clear and unambiguous – I want to be integrated – whatever definition is given."

Greaves, Mary. 'Contact' (Oct.-Nov. 1973), No.31, page 31. Liverpool Association for the Disabled.

After the initial success in mobilising disabled people and drawing parliamentary attention to our social isolation and impoverishment DIG started running into problems at two levels: which disabled people should receive any new 'compensatory' benefit for disability, and what action is required from the grassroots membership?

No government will provide an adequate income without clarifying where the lines should be drawn both for 'eligibility'

and how much should be paid. Too generous on either dimension will result in disincentives to 'earn' a living by means of employment or too many recipients dependent upon compliant taxpayers with 'capabilities'. Generous benefits criteria could even mean that not only would there be a disincentive for disabled people to obtain paid employment but also an *incentive* for people with capabilities to welcome the 'stigma' of disability as a means of avoiding the odiousness of unwanted employment!

Problems such as these in DIG's approach to integration inevitably leads to an extended role for 'eligibility assessments' in the lives of disabled people. Consequently DIG's leadership became increasingly preoccupied with the question of 'setting criteria for benefit questionnaires and tests'. This increased concern about 'definitions of disability'. Sorting out these challenges meant that DIG's grassroots membership was shunted aside as academics and researchers with capabilities gleefully debated and published their own versions of who we are and who should receive 'benefits'.

Harris, A., et al (1971) 'Handicapped and Impaired in Great Britain', HMSO gave legitimacy to this approach when they adopted prevailing definitions for their disability surveys in the UK. In the '*Union of the Physically Impaired*' (UPIAS) I counter-attacked by modifying their definitions and composed a social interpretation of disability. With the debate about benefit eligibility dominating academic disability concerns at the end of the 1960s it is no accident that UK experts reflecting on these debates played a key role in designing the WHO classification of '*Impairment, Disability and Handicap*'. It is in this context (DIG's campaign for a National Disability Income and the government's concern with limiting eligibility) that the seeds for the social model of disability were fertilised.

As the 'experts' forged successful careers on the back of the 'incomes lobby' ordinary DIG members increasingly lost any

meaningful role within the organisation other than providing numbers for demonstrations while the leadership courted the limelight in order to influence members of parliament. Consequently, the disability movement fragmented and went into rapid decline leaving the leadership elite isolated amongst an admiring circle of parliamentarians with capabilities (a scenario exactly duplicated some twenty-five years later when the disability movement's leadership moved into the 'rights and direct payments lobby' – the latter being the old-fashioned 'incomes lobby' touted up in modern form).

Despite DIG's essential failings, however, its contribution to the emergence of disability studies should not be written out of our emancipatory history. In my view the main significance, in this respect, was twofold:

Personal contacts and network building

Nowadays its easy to forget that at the end of the 1960s there was still little opening for disabled people to acquire the knowledge and skills to articulate our needs in public. Leading figures were few and sparsely spread around the country. It was during the branch and national meetings and the public demonstrations that DIG provided an opportunity for disabled people to become acquainted, exchange views and build a national network of contacts. This greatly extended the work already taking place in the more active local disability organisations.

Through DIG Paul Hunt, for example, made contact with Megan and Berit, Peter Large (who was also a founding member of the *Association of Disabled Professionals*), Selwyn Goldsmith (who was a government consultant on housing standards for accessibility), Peter Townsend (influential in developing disability related policies) and Ann Shearer (at the Guardian newspaper where she wrote about disability issues).

I mention a few names to highlight the fruitful link between the diverse and small group of disabled people and people with capabilities who actively reshaped the way disabled people's lives were interpreted in the 1960s. The modern disability movement did not spontaneously emerge but arose out of the efforts of particular disabled people and supporters with capabilities who made heroic efforts to challenge our oppression. These people often had different political affiliations and there was a dynamic struggle for ideas behind the diverse arguments for 'compensatory incomes' and what might be the most effective way forward for DIG.

The credibility of non-medical forms of assistance in the community

Prior to the emergence of DIG prevailing wisdom insisted that a medical, or medically directed, intervention was the only sensible way of dealing with the 'problem of disability'. When no 'cure' was conceivable then disabled 'patients' could carry on functioning with the provision of specialised lifelong 'care' under medical supervision. This approach I identified in 1981 as the 'cure or care' approach and it absolutely ruled the lives of disabled people. (Vic Finkelstein. *Disability and the helper/helped relationship. An historical view.* Brechin, A., Liddiard, P. and Swain, J. (eds) (1981) *Handicap in a social world*, Hodder and Stoughton.). There were no national organisations of *all* disabled people which directly challenged this attitude.

When DIG campaigned for an income to compensate for disability, however, it inadvertently:

- (a) Demonstrated that a non-medical approach to the social problems we face had wide support from a sizeable body of disabled people. It was now no longer possible to continue dismissing the right to an equitable life in the community as an argument of disabled individuals who were exceptions to the rule.

- (b) Dealt a body-blow to the hegemony of medical control. This reinforced pressure (generated by the 'assessment for benefits' debate) for a non-medical way of interpreting the meaning of 'disability' – i.e. a social model of disability to rebut the medical model of disability.
- (c) Gave credibility to the argument that disabled people are 'citizens' and not just lifelong 'patients'. This planted a seed for the argument later that 'social support systems', rather than 'community care', are the logical way of making social provision for disabled people's personal requirements – i.e. an approach which is informed by the social model of disability and not the 'cure or care' maxim.

SUPPORTING EMANCIPATION

By the late 1960s it was apparent that the costs of maintaining a large number of patients in long-stay NHS hospitals was raising economic concerns. This was particularly evident in the psychiatric hospitals (at the time variously referred to as the mental, geriatric and mental handicap hospitals – and frequently referred to as the 'bins' in personal communication between professionals). The development of new drugs and electronic innovations in environmental control systems was seen by government as a way of 'dumping' people back into the community rather than in institutions. Doubts about the endurance and suitability of long-stay institutions was fuelled by a growing body of research revealing poor living conditions, inmate dissatisfaction, inadequate staff training and incidents of abuse and victimisation. The tempo, then, was changing in favour of community 'care'.

That this could be just as expensive if appropriate community-based support systems were made available was not readily contemplated. As well as some work in preparing accommodation and ex-patients for life in the community only the retraining of staff also moving from institutions into the community was recognised as important but hardly thought

through. I was working as a clinical psychologist in the NHS at the time and we were asked to initiate some staff reorientation group-work, but this was hastily constructed and not advised by educationalists. The de-institutionalisation programme, then, had a marked effect on the need for new educational and professional training courses which relate to 'disability' concerns.

An emaciated response

As thoughts about long-stay institutions changed disabled residents in 'homes', already inspired by DIG's campaigning and influenced by the potential of the new environmental control systems, increasingly questioned why all disabled people could not live in the community. Doubts about the future of residential accommodation for disabled people was forcefully expressed in Le Court, the first Cheshire Foundation charity home. Perhaps because it was the first it attracted the most articulate disabled people lingering in hospitals and geriatric wards. Operational before rigid staff control was established residents exercised some degree of control over their lives within the 'home'. Le Court residents were very involved in publishing '*Cheshire Smile*' and this provided a platform for some of the most energetic discussions amongst disabled people at the time. As the NHS long-stay hospitals entered their period of radical overhaul agitation amongst Cheshire Home residents increased. I thought Louis Battye captured the mood in his 1973 article:

"Twenty years ago the homes represented a brilliant pioneering venture, a new concept for the disabled. But they have been overtaken by events ... The avant-garde has become the old hat. ... management of many homes is largely in the grip of small self-perpetuating middle-class circles ... there is little genuinely democratic control. ... They should have the right to choose, within the limits of their disabilities, the kind of life they want to live ... the Foundation would do well to engage in a radical rethinking of its traditional

policies. It might indeed be said that phase one of its great work to better the lot of the disabled, at least in this country, has now been completed. If phase two should prove as big an advance as its predecessor it will earn even more gratitude from even more people.”

Battye, Louis (Autumn 1973) '*Cheshire Smile*', Vol.19, No.3, page 15.

When the '*Union of the Physically Impaired*' (UPIAS) started to form in 1972, following Paul Hunt's letter in the *Guardian* suggesting a new organisation was needed, we began a process of rethinking the way 'disability' was understood. We also welcomed an exchange of views on the ideas and investigations that many disabled people were making at the time to enable *full and active lives in the community*. For me, this radical rethinking represented a new chapter in our history and I regarded the struggle to take control over our lives within the community as the rightful 'phase two' successor, if Louis Battye's view about 'phase one' was reluctantly conceded (**Finkelstein, Vic** (1975) *Phase 2: Discovering the Person in 'Disability' and 'Rehabilitation'* Magic Carpet (New Year 1975) Vol XXVII (1) pages 31-38).

It was in this fermenting climate of the 1960s that new management in Le Court attempted to impose much greater control over the residents than had previously been accepted. Searching for ways of opposing this management regression Paul Hunt and more active residents turned to DIG contacts and social research concerned with institutions to support their side of the argument. Dr Eric Miller and Miss Geraldine Gwynne of the Tavistock Institute in London were approached and it was suggested that they might research conditions in the residential institutions.

“Miller and Gwynne's involvement with segregated residential institutions first started in 1962 at the request of several residents, of whom I was then one, at the Le Court Cheshire Home in Hampshire. We were at the time struggling for representation on

management to extend the range of control over our lives and prevent the reinstatement of infringements of our individual liberty as expressed in such freedoms as, to choose our own bedtimes, drink alcohol if we chose, freedom for the sexes to relate without interference, freedom to leave the building without having to notify the authorities, etc. All of these had been hard-won extensions of control over personal life. We had thought, naively, that ‘experts’ on ‘group dynamics’ like Miller and Gwynne would be likely to support (and promote elsewhere) our struggle to build a community life in which residents took a really active part and shared in decision making. As is still the case today in every institution where the same struggle for participation continues, we needed every bit of help we could get. Resulting from our request, in 1966 Miller and Gwynne were financed by the then Ministry of Health to do a part-time pilot study lasting three years.”

Paul Hunt (1981) *Settling Accounts with the Parasite People: A Critique of ‘A Life Apart’*
by E.J. Miller and G.V. Gwynne. *UPIAS Disability Challenge* No. 1. 1981.

There is, of course, nothing at all *special* about aspiring to these personal liberties. The residents, then, only sought social research which would support them in achieving those rights which are universally recognised by people with capabilities for *themselves!* In what has become a notorious example of bigotry in ‘objective’ studies conducted by researchers with capabilities instead of focusing on attainment of human rights they turned their talents to the function of these institutions (as they are quoted by Paul):

“the essential characteristic of people who have been taken into institutions is not simply that they are crippled and, therefore, to a greater or lesser extent in need of physical care, but that they have been written off by society . They are in effect socially dead ... *(The)*

primary task of institutions for the disabled, is thus to cater for the period residents have between social and physical death.”

Paul Hunt (1972) Parasite People. *Cheshire Smile*
(Autumn 1972) Vol. 18 (3).

A critique of A Life Apart by F. J. Miller and G. V. Gwynne. Tavistock Publications and Lippincott. 1972.

Having switched their research from the operational needs of the residential inmates to the operational needs of the residential institutions they now applied their genius to identifying the most humane way of institutionalising the oppression of disabled people! As Paul Hunt, still quoting from Miller and Gwynne, argues:

“Their bias is embodied in the terms of reference of the Miller and Gwynne study. The terms of reference which they themselves proposed and which the Ministry of Health accepted, were in general terms, ‘to identify more precisely what was involved in providing residential care for incurables, and to discover possible ways through which appropriate changes could be brought about. ...

“Miller and Gwynne's interpretation of these vague guidelines is given in the words "to understand and try to tackle the problems of operating these institutions" (emphasis added), consistent with this, they claim to have shown that "it is possible both to arrive at more effective concepts of residential care and to recruit staff and train them to operate more successfully."

Paul Hunt (1981) Settling Accounts with the Parasite People: A Critique of ‘A Life Apart’ by E.J. Miller and G.V. Gwynne. UPIAS *Disability Challenge* No. 1. 1981. p.38.

And Paul concludes:

“Throughout their research, however, Miller and Gwynne restrict themselves to a narrow, blinkered

approach to the issue, i.e. to try to make the institutions work a little better. They recognise the institutions in question are oppressive, and say that entering them amounts to social death: similarly, they call institutional life a 'living death' and say that 'institutions have inherent pathogenic characteristics' and so on. (14). But they want to make them work a little better."

Paul Hunt (1981) *Settling Accounts with the Parasite People: A Critique of 'A Life Apart'*
by E.J. Miller and G.V. Gwynne. *UPIAS Disability Challenge* No. 1. 1981. p.39.

The 1960s upheaval in institutional provision added a spark to the smouldering struggles of disabled people and shook up the complacency of Cheshire Homes. Disabled residents became more robust in promoting and defending their basic rights. One unexpected result was that the Miller and Gwynne research and book appeared just at the right time to fill the gap opened up by the need for professional knowledge and expertise updating. The book was warmly welcomed by educators, not just for staff working in institutions, but for all workers with disabled people.

Despite the backward-looking recommendations Miller & Gwynne's investigation into residential 'homes' had a contrary, yet salutary, effect: it reinforced disabled people's determination to sort out their own route to emancipation! This intensified information gathering about the range of requirements to enable disabled people live in the community and it stimulated much further thought about the 'meaning of disability' as well as *who* determines this meaning. This immensely useful information filtered out from the struggles in institutions and disseminated widely amongst disabled activists, both in and out of the residential 'homes'. UPIAS had been set up during this period and, in the light of the Miller & Gwynne research travesty, its members strengthened their resolve to draw on their own experiences and information gathering in finding a way back into their own communities.

A satiated response

UPIAS was founded in response to the failing *Disablement Income Group* and the frustrated aspirations of disabled residents in institutions. Its main focus was the campaign for full participation in all sectors of society. This included State assistance:

“The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives.”

UPIAS Constitution, Aims and Objects (Adopted: 03.12.1974. Amended: 09.08.1976)

It is clear that the aims are comprehensive, embrace the requirements of *all* disabled people and, unlike many other organisations at that time, avoids single issue campaigning. This reflected the radical aspirations of institutionalised disabled people who, in seeking ways of returning to their home communities, had to address a multitude of issues *at the same time*. This contrasted with those already living in the community who sought ways of enhancing their quality of life by targeting outstanding, often single issue concerns, that impede their progress onto the next rung up the ‘independence’ ladder that they were already climbing (in contrast to the institutionalised disabled people who weren’t on *any* ladder). Seen this way it can be no accident that those deemed by Miller and Gwynne as “socially dead” turn out to be, in fact, the most radical and far thinking!

UPIAS attracted members from residential institutions around the country, those feeling threatened by institutionalisation and radical disabled people living in the community, as well as non-

disabled supporters. With UPIAS backing and emotional support Maggie Hines and Ken Davis, who had been variously incarcerated in the Sir Ludwig Guttman Hostel and Young Chronic Sick Units, explored options for moving into their own accommodation in the community. Their experience captures the innovatory spirit alive and kicking in the body of the 'socially dead'!

“When Paul Hunt publicly suggested that we should come together in this way it was a lifeline for me. The Union of the Physically Impaired Against Segregation was formed and as it developed many things about my situation came clear to me. I could see that I and my fellow inmates were victims of other people’s prescribed solutions to our problem. What we needed was that physically impaired people should define their own problems and their solutions out of their own direct experience of disability. ...

“The solution to my immediate housing/help needs had to be struggled for in advance of these required changes. When I met my husband-to-be we set about devising our own alternative to institutions and the principles on which it ought best to be founded. That we were able to achieve what we wanted says a lot for the individuals with whom we worked along the way. Our answer was a small development of housing units, some of which were designed with the architect to meet the specific needs of potential tenants identified in advance. Other units were to be let to non-disabled tenants who were willing to supplement the help available from local domiciliary services in meeting our need for support. This quasi-collective solution was developed out of our own perception of our needs – and as a reaction against the institutional reality forced on us by other people.”

Maggie Hines (1983) *Disability Challenge*. No. 2.
(1983) p.8-11. UPIAS

Ken Davis adds emphasis to the argument that the most oppressed disabled people with no alternatives within the established 'caring' services can be the most persistent in finding solutions:

"The seed idea came from physically impaired people whose aim was to find a way to live 'normal' lives integrated into the community. They wanted to get to grips with the dilemma facing many significantly physically impaired people whose only alternative to the family frying pan is the institutional fire. [Ken and Maggie] had direct personal experience of both situations. Deprived of a real choice, they joined with other disabled people to form the Union of the Physically Impaired, to struggle against segregation and for all arrangements necessary for us to participate fully in society."

Ken Davis (1981) *The UPIAS connection*. UPIAS *Disability Challenge* 1 (1981) 32-36.

In his analysis of what had enabled them to move out of residential 'care' and back into the community Ken suggests that there were three basic elements:

"In putting principles into practice, three basic elements interact to produce the basis for a high level of independent daily living for the physically impaired tenants. The first is good basic design; the second, the right aids and equipment; the third a secure, flexible system of personal help."

Ken Davis (1981) *The UPIAS connection*. UPIAS *Disability Challenge* 1 (1981) 32-36.

Now here's a thought: a mass organisation was set up by people living in the community centred on *incomes* (DIG) but people moving out of institutions and into the community don't mention money! Perhaps the 'incomes issue' is subsumed under Ken's element three – 'secure, flexible system of personal help'. In other words, a 'secure, flexible system' is,

within the context of nationalised (publicly-owned) services, a comprehensive state 'support system' and this includes financial benefits as needed? Note that the word 'care' is also absent! Whatever the interpretation, it seems to me that in the 1960-70s one sector of the disability community made an attempt to avoid 'piecemeal' solutions to our oppressive segregation.

"We are not restricted to one aspect of physical disability (e.g. mobility or incomes) ..."

UPIAS *Policy Statement* (adopted 1974, amended 1976).

The Miller and Gwynne story, the need to address a wide-range of issues to enable life in the community and disillusion with the blinkered monopoly in knowledge about disability issues policed by professionals with capabilities clarified the necessity for disabled people to gather and disseminate our own data bank of information. Drawing on their experience in sorting out housing needs in the community Ken and Maggie and colleagues were propelled into setting up the *Disability Information and Advice Line* (DIAL) to make information available as widely as possible to disabled people.

It should be remembered that in the 1960-70s, and still today, several professions working with disabled people specifically excluded us from qualifying in their field. This made it near impossible for disabled people to become knowledgeable about disability issues in certain areas. This is not only a career barrier for disabled individuals but excludes us from the influential bodies that determine public service and research funding.

The Medical Disability Society (MDS) formed in 1984. In 1985 there were two academic post in rehabilitation medicine – Prof. Lindsay McLellan, Europe Professor of Rehabilitation at Southampton University, and in Edinburgh the Chair was held by Cairns Aitken. “It should be pointed out that Lindsay is a neurologist and Cairns a psychiatrist – surely a good omen for the catholic approach to the management of disabled people and the severing of the links with rheumatology.” (my emphasis)
[<http://www.bsrm.co.uk/index.htm> Accessed 12.10.2004.] Say no more!!

A DIAL network spread around the country and this was reinforced by an escalating plethora of alternative information sources set up and controlled by disabled people throughout the UK; including TV, radio, journals and handbooks and more recently the electronic ‘internet’. It is this need for a *comprehensive* approach to the problem of ensuring disabled people can *live* in the community (i.e. not just ‘survive’, be ‘dumped’ or ‘cared for’ in the community) that keeps filling the knowledge portfolio until ready to burst into non-medical courses in disability studies.

An encyclopaedic response

The arrival of well-informed disabled people in the community from residential ‘homes’ added leverage to the arguments for change in the professional practice of community-based service providers with capabilities. While academic courses began presenting new materials to meet this need the experience of more radical disabled people had convincingly shown that service providers with capabilities simply would not respond adequately. It became imperative that disabled people started addressing the services problem by constructing their own forms of provision.

The search for a way out of residential institutions had led to the collection of information from around the world about appropriate personal assistance linked to accessible housing.

The *Fokus* scheme in Sweden attracted positive approval while, not surprisingly, the segregated disabled village, *Het Dorp*, in Holland (which Rosalie Wilkins visited and reviewed for the Sunday morning TV *LINK* disability programme and I lampooned in my TV *Very Cross Roads* cartoon about a disabled village) was ridiculed as the ideal fantasy of many people with capabilities. Knowledge about USA *Centres for Independent Living* (CILs) began to filter back to the UK in the 1970s and there was much interest in how this approach might be 'adopted' or 'adapted' here.

In 1980 I had an opportunity to visit the USA CIL in Berkeley, California, and having discussions with its former director, Ed Roberts who was currently director of the California Rehabilitation Services. He was a bit taken aback when I said that I was immensely impressed with what they had achieved but felt their approach was not quite appropriate for the UK! In fact I felt a project I visited in Houston, Texas, was a better experiment in service development between professionals with capabilities and disabled people. Located within a medical rehabilitation centre however, it seemed to me a little too subservient to traditional views.

My opinion was that although the 'nationalised' social services in the UK could, in theory, provide adequate support it was prevented (disabled!) from doing this. Because people with capabilities in the 'professions allied to medicine' (PAMs) exercised absolute control over the services, they shaped it into a '*caring for*' service instead of a '*support with*' network for us to realise our *own* aspirations. In other words the prevailing services were and are, in their construction, '*deliverer determined*' (designed by professionals with capabilities) rather than '*recipient requested*' (designed by people who are service users). This barred disabled people's entry into the power structures so that we could develop, direct and manage socialised community based services that we want and need. In the USA, where there was no comprehensive nationalised social service providing support to disabled people in the community, it made sense to start their own.

Towards the end of the 1980s progressive Occupational Therapists became increasingly aware of the radical ideas sweeping through the disability movement. At a London conference Rachel Hurst spoke of the need for far greater involvement of disabled people in the future development of the profession. This received a mixed reception but when disabled participants were fobbed off with vague promises of 'consultation' there was uproar. After much haggling in little groups agreement was reached that a 'working group' would be set up. We never heard from them again – and these were the 'progressive' OTs!

*The UK challenge, then, was to find a way of entering the social services structures that provide community-based services to disabled people so that the balance of **power** is changed in our favour. This, in my view, requires a different kind of worker (profession) embedded in the statutory services but working to standards set by 'disabled people' rather than 'service providers with capabilities'.*

Trying to enter the UK social services structure in order to change it rather than lobby from outside for reform was a daunting challenge: far more demanding than giving up, opting out of the nationalised system and heading towards the USA 'privatisation' model. In search of relief from the yoke of 'care' imposed by 'service providers' with capabilities many disabled people visited the Berkeley CIL. Some favoured its application directly to the UK but Ken Davis and the Derbyshire Coalition of Disabled People proposed fundamental changes which, at the time, seemed to open a more pertinent and radical route to community based services in the UK:

“During 1981 – the International Year of Disabled People – the newly formed Derbyshire Coalition of Disabled People suggested the establishment of a Centre for Independent Living in the County. In a significant step, the Coalition sought and obtained the

in-principle support of the County Council for the proposal. This set the scene for a collaborative approach to the development of practical services and facilities ...

“In taking this step the Coalition was conscious of a number of issues which seemed to be involved. These included the need to review the philosophy and practices of the independent living movement as it had-developed throughout the Seventies in the USA; the need to relate the development to the work of the disabled peoples' movement in Britain over the same period ...”

Ken Davis (December 1984) “Notes on the Development of the Derbyshire Centre for Integrated Living (DCIL)”.

(Leeds University Web Site – <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>)

In relating the USA CIL movement to the UK, therefore, it was decided to call the Derbyshire CIL (DCIL) a ‘*Centre for Integrated Living*’.

“The use of the term ‘integrated living’ is an attempt to make clear and get in context both the end and the means of the DCIL. It aims for the full social integration of disabled people and it seeks to achieve it by disabled and non-disabled people working together. Its constitution builds this mutuality into the various components of control – into its General Council, Management Committee and Sub Committees, and its policy is to duplicate this same process on the ‘shop-floor’. The DCIL is also integrated into a strategy for the development of Social Services which also has as Its Aims the integration of disabled people into the social, economic and political life of the County. In turn, this strategy is being jointly developed with the Health Authorities, and DCIL is seeking also to integrate

representation from other statutory and voluntary bodies into its management structure. The commitment to integration is being pursued both in theory and practice.”

Ken Davis (December 1984) “Notes on the Development of the Derbyshire Centre for Integrated Living (DCIL)”.
(Leeds University Web Site – <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>)

Drawing on the experience of DCIL the *Lambeth Centre for Integrated Living* (LCIL) followed the same *integrated* CIL model. In planning for the *Independent Living Support Worker/Assessment and Aid Officer* for the proposal, for example, Dick Leaman put it this way:

“... The orientation of work would simply be to do with whatever supports a disabled person to be active, independent, and achieving the goals that they set for themselves.

“It is envisaged that the post-holder will make assessments and prescribe aids in much the same way as community Occupational Therapists: and that their recommendations will be accepted by LBL Social Services as a means to access their budgets for aids and adaptations.

“However, CIL is fundamentally not about providing the same services in the same way as existing agencies: and it is not envisaged that the post-holder will have a background in professional O.T.

“O.T. as a profession has grown out of medical models of disability, and it has rooted itself in disciplines of anatomy and physiology. In this way it has accepted design norms, and noting the incompatibility of disabled people with these norms, it has sought to adapt and modify what is given to meet what it has come to define

as disabled people's 'special needs' (the administrative model of disability). The CIL post-holder would, on the other hand, come from a different position, probably based in ergonomics, engineering and design. Whilst serving the same problem-solving function as O.T., this person would focus on bad design and improving of the built environment to meet the needs of all members of the community, regardless of their divergence as minority groups from social norms (the social model of disability)."

(my underline)

Dick Leaman (March 1989) 'Proposal and budget for a Centre for Integrated Living, to: West Lambeth District Health Authority Community Unit'. Lambeth ACCORD, London.

This is nothing less than a planned assault on the medical model! The creation of a pristine profession managed by disabled people in a new-breed centre to support the aspirations of disabled people is a radical departure from the USA CIL model. A central feature of centres for 'integrated' living then, is that the services it provides and manages are neither wholly 'independent' (in the USA style) nor 'consultative' (as many in the UK had been pleading) but 'integrated' (within the statutory decision-making bodies). In my view this approach is informed by the radical social model of disability and engages 'disability issues' by tackling the disabling society rather than by creating islands of integration within a sea of segregation! The consequence cannot help but transform health and social welfare provision:

"The point is ... to foster new initiatives and new kinds of service provision, according to disabled people's own perception of our needs."

Dick Leaman (March 1989) 'Proposal and budget for a Centre for Integrated Living, to: West Lambeth District Health Authority Community Unit'. Lambeth ACCORD, London.

I believe that during the period 1970-1990 disabled people amply demonstrated that we have been most successful in pursuing emancipatory goals when we have addressed the social problems that we face *uninhibited by precedents set by people with capabilities*. Trying to modify existing services while retaining the core power relations has conclusively proved to be a dead end.

Ken Davis summarises the professional barrier faced by disabled people during the era in which CILs were developed:

“Throughout the years of disabled people’s self-organisation and collective struggle, what has been most fundamentally amiss boils down to two main issues: first, a limpet like attachment by the disability establishment to a ‘medical model’ view of disability; second, the disproportionate distribution of power and influence between those who control disability policy and disabled people themselves. The weight of policy and practice still largely rests on the backward but convenient tradition of assuming that disabled people are different, have special needs and that their dependence requires the intervention of properly trained people who care and provide for them.”

Ken Davis (1996, updated 1998) “The Disabled People’s Movement

– Putting the Power in Empowerment”.

Paper for a seminar at Sheffield University Sociology Department 1996, p.4.

(Leeds University Web Site –

<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>)

SUMMARY

In the late 1960s a major convulsion shook the complacency of service provision for disabled people in the UK. This triggered a pressing need to modify established practice in the community. For service providers with capabilities this meant *adapting* long-standing practice while maintaining the traditional

power relations with service users (i.e. ‘care in the community’); for disabled people this meant *radically rethinking* lifestyles and creating entirely new ‘community based support services’ (i.e. CILs). During the 1970-80s, then, disabled people met the challenge and set about investigating different ways of providing their own approach to support systems.

In addition to the pioneering ‘Centres for *Integrated Living*’ there were also ‘Centres for *Independent Living*’ in the UK more closely modelled on the USA CIL brand. The fundamental difference between ‘Centres for *Integrated Living*’ and ‘Centres for *Independent Living*’ was sharply highlighted in the 1990s when the weight of national party politics shifted and the centre left Labour Party jumped over the central Liberal Democratic Party to occupy a centre right position, pushing the Conservative Party further to the right. This changed the political balance leaving no major national party with a ‘socialist’ agenda. Both the Derbyshire and Lambeth ‘Centres for Integrated Living’ were soon in crisis – the former became a “Centre for *Inclusive Living*” and the latter was dismantled. On the other hand ‘Centres for *Independent Living*’, facing a greatly weakened ideological opposition within the ‘disability movement’ were now free to develop, rewrite history, and present their approach as the originator of CILs in the UK!

The government’s shift towards ‘care in the community’ had encouraged disabled people in residential homes to contemplate their future far more comprehensively than could be supported by DIG’s proposal for an income to ‘*compensate for disability*’. Residents from institutional ‘homes’ tended to emphasise appropriate personal support, accessible housing in the community and an equitable income. This required a global, rather than a piecemeal, or DIG’s *single issue*, way of tackling our needs. In other words – the less severe the person’s impairment (or the more they are like people with capabilities) the more they are likely to look for single issue

solutions to their needs in the community; the more severe the person's impairment (or the more they are unlike people with capabilities) the more comprehensive are their solutions for life in the community. This is why ideas arising from *dependent* disabled people contemplating their move out of residential homes tend to be far more radical than those already in the community – perhaps a salutary lesson for aspiring academics in disability studies!

Independent living is a lie. Human beings are by nature dependent. That is why we live in societies. We are dependent upon assistance in gaining access to plentiful clean water, in-house electricity and gas, diversity in entertainment, a multiplicity of transport, support in maintaining our homes and care when we are ill, etc. In fact, life in modern society is inconceivable without being dependent on others for assistance. Disabled people, of all human beings, should know this and to pretend otherwise is to accede to a humiliating deception propagated by USA cultural imperialism. In my view disabled people will begin making their own unique contribution to the general well-being and knowledge about human nature when we fearlessly challenge the 'independence lie' championed by protagonists of the competitive market economy. Disability studies, if it is to become a civilising instrument for challenging the stupidity of bodily perfection at the expense of '*ahimsa*' cannot blend into the dominant cultural landscape painted by people with capabilities. In this picture we will always stand out mutilated (crippled!), irrelevant and rather pitiful.

We need our own set of standards based on *our* interpretation of the quintessential human paradox – that is, we are '*able*' precisely because we are '*socially dependent*'. I don't believe disabled people will make any lasting progress as long as we gawp in awe at the interpretation of '*independent ability*' displayed in the gallery of human nature constructed by people with capabilities. Playing word games to make our goals acceptable to people with capabilities is a formula for failure. Disability studies needs to assert its own non-disabling

academic agenda with matching vocabulary. This is what became possible at the Open University in 1960s.

The need for new educational and professional training courses arose at the beginning of the period I would identify as *Phase 2* in our emancipatory history because:

- The government policy on closing institutions stimulated preparation of updating courses for professional practice,
- The DIG campaign for an income to 'compensate for disability' brought into being a network of disabled people contemplating non-medical approaches to disability issues,
- Increased focus on disabled people living in the community raised greater awareness about accessible environments,
- Institutionalised disabled residents explored a variety of support systems for life in the community and
- Disability studies had to be something new – not another version of rehabilitation!

DISABILITY STUDIES

In the early 1970s ideas were floated for the presentation of an Open University updating course for teachers in '*Special Education*'. It was decided, however, that the course should be wider and cover all aspects of professional service provision related to supporting disabled people in the community. The course team was initially chaired by Professor Phil Williams who, I believe, was based in the faculty of education. By the time the learning materials were mailed to students in 1975 the course was chaired by Dr Vida Carver and it had become the first UK presentation in '*Disability Studies*'.

Vida was a most remarkable non-disabled person. A single parent, she earned her living as a secretary while studying part-time for a psychology degree. She then obtained a post at the Central Council for the Education and Training of Social Workers (CCETSW) where she concentrated on access issues for people who were hearing impaired. It was here that she extended her contacts with disabled people and the issues

stirred up by DIG. Vida was especially friendly with Mary Greaves, a leading disabled person heavily involved with DIG at the time. When the OU was set up Vida became one of its very first academics. She was based in the London regional office where she worked as a Staff Tutor in the Faculty of Social Sciences.

Vida was very special to me. At a time when *disability* was regarded as the preserve of the medical profession Vida almost single-handedly managed to create a course at the Open University which broke through centuries of prejudice and rigid assumptions. She saw disabled people as having a rightful place in the community and made sure that the new OU course had this theme at its centre. The course, then, was really the first that began to see disabled people's lives not purely in terms of the problems they may possess but arising out of the barriers that they confront when trying to integrate into the *normal* world. She went out of her way to ensure disabled people contributed to the course content and were recruited as course authors and tutors whenever possible. She actively encouraged my involvement in the first course presentation and welcomed my recruitment to the OU full-time academic staff, doing everything possible to sort out access issues which, until then, had not been properly considered.

When I first entered the OU campus at Milton Keynes as an academic in 1975 'access' issues for disabled people had not been seriously thought through. There were stairs randomly dispersed along corridors, multi-storey buildings with no lifts and only two barely accessible toilets on the whole campus. I shared a ground floor office with Vida in a building that I had to enter via the rear. Female toilets were on the ground floor and male toilets on the inaccessible upper floor; otherwise the nearest accessible toilet was at the refectory some considerable distance away. Vida made a sign which was fixed to the door whenever I used the toilet after any women inside were shooed out!

It took a year and a ferocious row before Vida got her way and hired a disabled person for the course team who was looking for her first secretarial job. Hostility came from head of the unit at that time who argued that a disabled person couldn't do the work and would be a burden to other staff!

Superficial 'political correctness' maintains that *only* disabled people can actively engage in our salvation. History shows, however, that *individuals* from the non-oppressed population can play a significant, sometimes even 'leading', role in an emancipatory struggle. A little thought on this explains why this might come about. An oppressed group, by definition, is denied access to the wherewithal for addressing *all* the problems it faces (e.g., entry to accumulated social knowledge, an independent income enabling freedom of action). Non-oppressed people, on the other hand, do have this opening. The ability to identify with others is a basic human condition and *some* non-oppressed individuals do connect with the oppressed, making their personal assistance, social confidence, general knowledge, access to information and financial reserves, ability to move freely in society, etc., available to the emancipatory struggle. However uncomfortable people may feel about the role played by non-disabled people in our struggle it is impermissible that this *reality* should go unrecorded or even written out of our history.

THE OPEN UNIVERSITY

A few words on the OU: The proposal to set up a 'University of the Air' in the 1960s was greeted with wide scepticism, especially from the established academic community. There were, however, a number of enthusiastic advocates for the correspondence based university who were critical of teaching practice in higher education and saw the proposal as an opportunity for creative revision in higher learning.

"I was persuaded that the standard of teaching in conventional universities was pretty deplorable. It suddenly struck me that if you could use the media and

devise course materials that would work for students all by themselves, then inevitably you were bound to affect – for good – the standard of teaching in conventional universities.”

Professor Walter Perry, The Open University’s first Vice-Chancellor.

History of The Open University, 01.03.2004.

www.open.ac.uk

There was much debate about suitable content for course presentation compliant with distance teaching and the appropriate structure for academic units. While some favoured traditional structures others argued for a radical departure. Concern about credibility in the eyes of the academic establishment led to a compromise. While the recognisable faculty units would be maintained, courses were to be ‘topic’ rather than wholly discipline determined. This enabled academic staff based in their related discipline faculties to participate in course production together with others from all academic units in the university.

Prior academic standards were initially not a requirement and anyone could register as an undergraduate student provided they were English literate, over 18 years and lived in the UK. Not surprisingly the new multi-media correspondence university immediately attracted large numbers of disabled pupils. As an oppressed group we had been denied access to higher education either because of non-accessible facilities or through exclusion from ‘normal’ schools and the OU was seen as an unexpected educational opportunity. The influx of disabled pupils was greater than all the higher education institutions put together! This immediately raised ‘distance teaching’ access issues and a Disabled Students Officer was appointed. The post was filled by Geoffrey Tudor the retired head, if I remember correctly, either from a ‘Spastics Society’ school or Hereward College. (Hereward College was a ‘special’ further education college for disabled students. Bert Massey was one of its ‘luminaries’ and it was here that seeds for the future

Graeae Theatre Company and 'disability arts' were sown. Some of the latter's founders having been at Hereward).

Vida took an active role in the OU Disabled Students Office and this further widened her disability network contacts for the future disability studies course. She was particularly active in promoting the provision of audio tapes of the home study Workbooks and course Readers, often reading material onto tape herself. Arrangements were made for study groups to enable Deaf and hearing impaired students access to courses and Vida participated in the development of this service. Having in mind that not all students had access to radio and television at the broadcast times this material was generally regarded as 'supplementary' and not a requirement for course completion. Some provision was made for home tuition for students who had been unable to attend the regionally-based tutorial groups.

A home study kit was mailed to students where courses required some laboratory work, but courses aimed at professional qualifications or professional updating posed a different set of distance teaching problem. This was especially so in areas such as teacher qualification and training where classroom access was required for teaching skills to be assessed, and nursing where hospital ward access was needed, etc. A committee was set up to look at 'serving the educational needs of the community' and this led to the establishment of a 'Post-Experience Courses Unit' (PECU) where continuing education, post-experience study and professional training courses could be developed. Members of the Faculty of Education were amongst the first to be interested in producing professional updating courses in the new PECU unit.

With the completion of the OUs first university level foundation courses in the 1970s some academics turned their attention to the proposal for a half credit course in '*Special Education*'. Although Vida was based in the London Regional Office as a Faculty of Social Sciences' Staff Tutor she took an immediate

interest in the new course discussions and joined the embryonic academic team. Her increasing involvement in this project eventually led to her move from the regional office to the central campus in Milton Keynes where she became a 'central academic' based in the new PECU unit. Drawing on her vast experience and contacts Vida argued for the original proposal to widen out and embrace the broad range of issues confronting disabled people living in the community. The proposal now focused on issues related to disabled people living in the community and it was presented in 1975 as '*The Handicapped Person in the Community*', being the first '*Disability Studies*' course in the UK.

THE HANDICAPPED PERSON IN THE COMMUNITY

There were only a few OU academics sufficiently knowledgeable about contemporary 'disability' issues to begin work on '*The Handicapped Person in the Community*' course. It was, therefore, thought essential to start production with the backing of potential contributors and well-disposed service providers. The course team set up a consultative meeting which was well attended by most of the 'leading figures' of the time. From this meeting ideas emerged for the course content and possible contributors to the study texts, set books and Reader, case studies, radio and television programmes. All these materials were mailed directly to student homes; the radio and TV components were broadcast on the BBC. With 1,200 students in the first presentation year and open public access to the BBC radio and television broadcasts, a very large UK population was exposed to the 'vanguard' of non-medical approaches to support disabled people living in the community. The Reader (a world's first) was very popular and widely used in disability related courses for many years.

Some 8,000 to 10,000 students followed the course over the years in its various remakes from 1975-1998 when it finally ended. I have not the slightest doubt that this OU course with its sizable studentship from all parts of the country had a significant, unresearched and rather shamefully unrecognised

influence in changing the cultural climate for service provision and the development of disability studies in the UK. In later years as former students advanced up their career ladders many became influential in their professions and at the very least alert to the contemporary social concerns of disabled people and the new terminology (e.g. the 'social model of disability')! An added bonus of the OU 'open' policy to distance teaching was that students with different academic backgrounds, with or without professional qualifications, and direct or indirect interest in the subject, all studied the same learning materials. When attending their local study groups, where disabled service users and professional service providers mixed, views could be exchanged on an equal basis. As an oppressed group the number of disabled people studying the course, given that it focussed on service provision, was rather small but the experience greatly enhanced confidence in promoting our views about disability issues.

The course, too, gave the stamp of academic approval to arguments for progressive service changes and boosted the morale of those disabled 'activists' who studied or just knew about the course. At a time when disabled people's views had fractional professional credence the timely appearance of the new Open University course shifted the balance of ideological, if not material, power. The original 200 hour course presented in 1975 included personal tuition, assignments and an end of year examination. Together with the correspondence texts this ensured a high standard was maintained in the quality of teaching. This halted the 'disability establishment' making any public criticism of the new non-medical course.

In its early years some member doctors with capabilities of the *British Society of Rehabilitation Medicine* (originally founded in 1984 as the *Medical Disability Society*) took umbrage with the Open University (OU) '*Handicapped Person in the Community*' course which was seen as intruding into their domain. Armed with its mission "to promote the understanding and multidisciplinary management of acute and chronic disabling diseases and injuries; their personal, interpersonal and social consequences and to advance public education in these matters" it was felt that this provided the right of intervention in how and what was taught by *anyone* about 'disability'.

When the OU presented its courses in disability studies it attracted students from a wide range of professions as well as disabled people throughout the UK. In due course the correspondence materials came to the agitated attention of a newly appointed medical lecturer with capabilities in rehabilitation at a southern England university. He wrote to me expressing dissatisfaction with the lack of medical supervision in the preparation and presentation of the course and requested a copy for his scrutiny and approval. Such a demand, of course, would normally be regarded as completely improper between academic colleagues across different disciplines. Since the OU course was publicly available in any case I sent him a copy and in exchange requested a written sample of his course! I never received a reply and I can only assume that he felt mortified by the quality of the presumptuous non-medical course.

The social issues and personal assistance concerns of disabled people could no longer be glibly interpreted as either *supplementary* (or *allied*) to medicine (*PAMs* – as Physiotherapists and Occupational Therapists see their role) or as the *rehabilitation* offshoot of medicine. But then the question

arises “To what discipline does the new type of course rightly belong?”.

It clearly did not belong to the medical discipline, but included a workbook in this field; it could not sit comfortably in an academic department of economics, but had a unit covering the ‘costs of disability’; it was not designed for a Faculty of Education to cover ‘special education’; but included material about education; it was not about ‘care’, but contained material prepared by Eric Miller on institutional life. The course also included workbooks on issues related to auditory, visual and motor impairments (environment access), as well as community based support systems to help people with ‘learning disability’. In addition to the more generalised material in the introductory unit the course included a workbook on the ‘goal setting’ approach to personal help.

*The broad overall sweep of the new topic based course and its inability to slot happily into any extant academic ‘home’ must mean, despite many imperfections, that an entirely new ‘academic family’ had been created – and this can only be interpreted as **disability studies!***

The Handicapped Person in the Community course was a solid foundation for developing courses in disability studies at the OU for 23 years. During this time I think three evolutionary stages in the course can be identified:

- P853 (the original course): Here ‘disability’ is still seen as personal and involves definable impairments to the body and its functioning. The course aims to improve understanding the way these impairments affect the disabled individuals ability to function in the community. This, it is hoped, will improve professional skills in treating, managing or responding to the special needs created by specific impairments. The course theme, however, emphasises the aim of professionals assisting disabled people to function fully in society. Social adaptations are considered as part of enabling disabled people ‘achieve maximum autonomy’.

- P251 (the first revision kept the original course number before changing): All material relating to the Miller and Gwynne research is removed and a more questioning approach to disability assumptions is encouraged. 'Disability' is now seen as involving a relationship between the person and the social and physical environment. This means supporting disabled people having greater involvement in the way that they live their lives. 'Collaboration' in the development of services is suggested. The new version also raises questions about what or whose interpretation should apply to the problems faced by disabled people and how helpers and helped may work together.
- K665 (the final version): The course emphasis is now firmly concerned with understanding 'disability' from the viewpoint of disabled people – that 'disability' is the result of disabling barriers and the basic issues are concerned with citizenship and democratic rights. 'Disability' is now interpreted as social rather than personal. Changes which remove disabling barriers are given much greater significance.

The innovatory cultural climate at the OU in its formative years cannot be stressed enough – everything they were trying to do was new and this is why it provided fertile ground for the new disability studies discipline. Although the term '*Disability Studies*' is used fairly freely now, it had not been used in an academic context in the UK until I first used the term for the Open University course *Changing Practice* published in 1990. In this material, which was marketed nationally and internationally, I wrote: "While you are not expected to be an experienced Group Leader in *disability studies* you should feel confident that you do have the appropriate skills before running a group with these materials." (K665x '*Changing Practice*' Group Leader Notes. Open University, 1990). Since then I used the term 'Disability Studies' as an accepted descriptor for the courses that we were developing in the OU and the term started appearing elsewhere in the UK.

The tortuous history of disabled people's emancipatory struggle demonstrates over and over again that real progress has only been possible when we abandon the goal of assimilating, or being included, into the social structures created for the convenience of people with capabilities. This was beautifully demonstrated with the emergence of disability studies at the Open University where it was possible for the new courses to owe *no* allegiance to established academic disciplines or faculties. If disability studies is to flourish I cannot see this being possible unless it creates its own 'abnormal' academic environment and educational standards, and explains why this is necessary. That is surely the legacy of the OU contribution to our emancipation. In my view 'disability studies' cannot be a branch of 'sociology' or any other established academic unit without becoming stunted!

SUPPORT SERVICES

If I concede that *Phase 1* in our emancipatory history involved the institutionalisation of 'destitute' disabled people and during this period 'care interventions' came into being; that during *Phase 2* disabled people with their 'care' dependents migrated back into the community where the notion of 'personal assistance' came into being; then *Phase 3*, it seems to me, should involve disabled people reclaiming their citizenship and developing a new 'community based support profession'. In other words when I review the different 'phases' in our progress towards emancipation each 'phase' can be seen as generating its own approach to service provision according to the changing circumstances imposed on disabled people.

Seen within this historical framework, then, the fundamental responsibility of disability studies, if it is to make an emancipatory contribution to this latest 'phase', is to house the development of a new community based support service and profession. An important lesson from the DIG experience, the relocation of disabled people from residential institutions back into the community, and the first OU 'disability' course is that the knowledge base for such a professional qualification

housed in an academic department of disability studies would have to be multi-dimensional; it cannot be single-discipline based; such as sociology or medicine. Such an academic department, then, would need to be filtered from selected relevant professional practices as well as incorporating ideas from diverse fresh fields such as architecture, design theory, aesthetics, ergonomics, linguistics, etc., and even medicine! But above all the whole exercise needs to be innovative, involving creative solutions distanced from traditional approaches invented by people with capabilities. A totally clean page is needed so that we can sketch our view of the services and expertise needed to meet our *practical* requirements for participation in society: a society in which we also have rightful political *power* to impart our own contribution to the general welfare.

Failure to set 'practical' goals for disability studies could very easily mean that the new discipline drowns in irrelevance, facilitating abstract academic concerns, sterile research, debates and conferences. Then, all that is achieved is the advancement of careers that are more empowering for the academic and researcher than anyone else. I've called this danger '*Oliver's jibe*' after Mike Oliver's overly severe criticism of his own research career (Vic Finkelstein (1999) Extended Book Review. Disability and Society Vol. 14, No. 6, 1999, pp. 859-867. Review of Colin Barnes, Geof Mercer (Ed.) (1997) Doing Disability Research. Leeds, Disability Press.).

Creating something as entirely different as a new profession in the face of powerful vested interests is no less a daunting challenge than that faced by the newly appointed Open University academics when they contemplated the way ahead. That they succeeded is evidence of what *is* possible provided the time is ripe and the right people are not only involved but also enthused with creative vision. This is why disability arts and culture, where imaginative thought can be *energised*, is such an important component in our emancipatory repertoire. It is in disability arts that we can bring vitality and enjoyment back into the science of understanding humanity and its welfare

needs. Such creative imagination is absolutely necessary for the development of a new support system free from the chains of tradition; and it is this 'creativity' that is stone dead in the existing mentality of 'care' provision, no matter how 'excellent' it is graded!

Seeding an innovatory culture within disability studies will enable us to harvest the necessary 'conspicuously different' knowledge base that more accurately mirrors our noticeably different social status and support service needs. This requires nothing less than shaking off *ethnocentric ableism* (the dominant culture whereby people with capabilities see themselves as the measure of all that is 'able') and questioning every presumption handed down to us by the grandees of the disability industry. Rather than spend time teaching and researching the meaning of words and language such as 'stigma', 'rehabilitation', 'care', and the WHO classification we ought, really, to teach and research how these concepts came into being, who promoted them and what purpose they serve in maintaining our dependency upon people with capabilities. Disability arts and culture already lampoons many of these moronic concepts and disability studies has a lot to learn and share with this sector.

We need to learn how to look at 'the *given* world' afresh, through the multi-coloured lens of the 'social model of disability'. A fruitful way of exploring alternative interpretations of any doctrine is to turn its axioms upside down and see if the logic still holds true (a kind of non-Euclidean wrestling match with disability related words!). For example, we might explore the WHO approach to definitions of 'disablement' by posing alternative definitions of 'capability' and seeing where this leads us. The '*International Classification of Impairment, Disability and Handicap*' (ICIDH – keeping to the original concepts) could become '*International Classification of Repairment, Capability and Footicap*' (ICRCF – mocking the original concepts) as a way of satirising the status of people with capabilities with *our* classifications. Walking, after all, for anyone who has watched the TV home video broadcasts showing people with capabilities

endlessly falling over their legs, is a far greater health hazard than mobility via a wheelchair! In modern society without their special mobility aids, like 'shoes' people with capabilities would quickly become 'housebound', refused employment, impoverished and dependent on charity. People with capabilities would have to sleep on the floor, endure backache and sleepless nights if they were denied access to their specially designed sleeping aids like beds. In the context of 'health' then, a classification of 'capability' should be perfectly possible with its own peculiar rating scales of dependency. I'll leave further examples of the dangers inherent in the dependency on 'bipedal mobility' to disability arts ... We should not forget, too, that about 80% of all people acquire some significant impairments during lifetime – making this condition 'normal' and not at all 'special' to our species!

As with all matters related to 'disability', disability studies will stagnate, presenting only moribund conferences as long as we copy routines established by people with capabilities. Emancipatory conferences have to be innovatory simply because conferences run by people with capabilities are not emancipatory and, in the context of dominant standards set by people with capabilities, issues of concern to disabled people are atypical. If it is in the 'nature' of disability studies that it cannot be squeezed into a single traditional discipline without becoming 'disabled' (!) then our conferences should reflect this. For a start, in my view, we need to engage the local community of disabled people, wherever we meet, at all levels in the decision making and conference participation. This will help challenge cherished procedures whereby academic concerns, in the interests of 'objectivity', maintain some distance from the very community about which they are supposed to be concerned.

Speaker presentations, for the most part, can be abandoned (with no loss) by ensuring selected, and *relevant*, papers are circulated well beforehand – making them permanently accessible electronically. The absence of boring readings from a front table or platform will free time for members of the local

disability community, researchers and academics to fill with interactive collaboration in designing and presenting practical solutions for unified themes set by each conference. Disability studies needs to create emancipatory conferences which engage the expertise from a wide range of professions.

The Open University experience shows that when a disability studies course integrates students from diverse fields such as health and social services, architecture, economics, culture, linguistics, medicine, education, etc., as well as non-professional disabled students in a shared learning situation this encourages unpredictable, but refreshing, interactions. I found that 'care' professionals regarded the broad topic based OU course enlightening and they expressed confidence in its relevance for their work with disabled people. However, they commonly reported frustration with their inability to put new-found course insights into working practice. They emphasised that the Health and Social Services commitment to the 'social care' paradigm imposed constraints on practitioners which they were unable to challenge or change. In fact, the trend towards strengthening 'care' guidelines under the pretext of improving 'excellence' has, in my view, now actually made reform of existing services even less feasible.

In the light of the past 40 years, then, I am convinced that we have reached a point in our emancipatory history where we face the biggest challenge yet – establishing an entirely new support 'Profession Allied to the Community' (PAC).

Setting the development of a new community-based profession as the main agenda raises critical issues for the major disability studies national and international conferences. If these are to differ from established practice then a good South African Zulu word for a special type of meeting comes to mind – 'indaba'. An 'indaba' is a broad-based conference which not only involves democratic discussion between 'leaders' and 'ordinary' people but concludes with decision-making for further action. As the 'indaba' moves from place to place and country to country the relevance of disability studies to disabled people

will become clearer to all and engage more people from the grass roots in their own destiny.

Emancipatory research, then, could be informed by these conferences, making research more than just investigations carried out by disabled academics but studies which also engage non-qualified disabled people in setting research goals and procedures, etc. Emancipatory research would become a 'tool' for addressing problems chosen by the community and the researcher would become an agent of the community alongside the new profession allied to the community. Such research could not only address issues 'out there' but at the same time, and within the social model of disability, provide deeper understanding of itself – i.e. 'disability studies' – what it is, why and how it has emerged at this point in time. It is in this respect that I feel disability studies will feel its way towards shared goals with other oppressed groups – identifying common factors in our emergence and common goals in the transformation of health and welfare social systems.

The lifestyle of disabled people, perhaps more than any other social group, is a celebration of humanity. Disability studies should reflect this by moving way beyond just focussing on the *problems* we face when forced to live in societies designed by people with capabilities for people with capabilities. In this way *Disability Studies* can become a leading tendentious scholarly centre and not just a replica of traditional faculties. It is here that the sagacious practicalities of an entirely new community based support profession can be translated into learning materials.

“It is still at the earliest stage of speculation to consider what will be the future of services for disabled people when informed by the social model of disability . This is when the untravelled road from fantasy to reality is at its most confusing and daunting but, nevertheless, challenging, stimulating and exciting.”

Vic Finkelstein and Ossie Stuart (1996) *Developing New Services*.

Hales, G. (ed) (1996) *Beyond Disability: Towards an Enabling Society*. Sage.

The innovatory challenge of 'disability' is, in itself, both universally reflective and predictive of human nature:

“What seems to me undeniable is that one of the factors in any progress towards a better society is the willingness of people to take theoretical and practical ‘leaps’ which sceptical common sense regards as unrealistic and idealistic. This is not to say that hard thinking, painstaking research and cautious experiment are not indispensable. The point is that they become sterile without imaginative vision and commitment.”

Paul Hunt (1972) *Parasite People*. *Cheshire Smile*
(Autumn 1972) Vol. 18 (3).

A critique of *A Life Apart* by F. J. Miller and G. V. Gwynne. Tavistock Publications and Lippincott. 1972.