

EMANCIPATING DISABLING STUDIES

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1. Introduction: the vulnerable

Human beings are, by nature, frail animals. At the best of times our eyesight cannot match the eagle-eye of a bird on watch, we are deaf to the sounds animals on the hoof can hear in the open plains of Africa, and compared to the fine senses of a dog sniffing for contraband drugs we could be just as well permanently without a sense of smell. We are outpaced in speed by herds of runners hunting or being hunted, and compared to birds we might indeed be mistaken for sedentary animals. However, in comprehending and dealing with this reality we have been remarkably successful. With our 'aids and equipment' we can see both further into space with telescopes and inwardly into matter with microscopes beyond the capacity of all seeing animals. We can hear sounds from outer space and the telephone enables us to hear a whispered word from the other side of the earth. Our machines enable us to move faster and further in the air than any others and our ability to manipulate the environment is not only creating an artificial world for ourselves but also for all living things, including those with superior physical prowess to ourselves.

At the centre of this achievement has been our ability to turn 'vulnerability' into a strength. Put simply, our 'natural' frailty has served as an incentive to cultivate extreme flexibility in interpreting ourselves and the world in which we live. Building on the application of interpretations that have been passed on from generation to generation we have acquired an accumulated body of knowledge which has enabled us to transform the 'natural' environment into a 'social' world of our own making. This singular 'adaptability' is a truly fundamental attribute of being 'human' and the point of departure between the natural and social worlds. It is arguable, however, that precisely because our capacity for 'flexible thinking' has been so successful that we have lost sight of the emergent rigidity in the categories into which the social reservoir of knowledge have been assigned. Today, we are faced with a plethora of professions and academic disciplines each of which jealously defends its own territory.

Nowhere does this success in intellectual adaptability degenerate more comprehensively into dogma than in the lives of disabled people. Acquiring an impairment in the natural world, at birth or adventitiously later in life, can place any animal's survival at risk even at the best of times. In the social world, however, experience in managing human frailty has provided us with an amazing cornucopia of interventions that make possible the survival of those possessing the greatest physical and mental deficits. But the body of knowledge gained in progressing this advance has been the property of a very narrow assembly of practitioners and academics. In time this has crystallised into institutional menus of good practice expected from medical staff in rehabilitation centres, occupational therapists in social services, remedial teachers in special education, and so on. In all this activity the volume of understanding has increasingly rested on what, until recently, has been an unchallenged dogma: that the possession of an impairment leads to social vulnerability. This is despite the fact that history teaches us precisely the opposite: that the natural vulnerability of human beings has significantly shaped the development of all the machinery of modern social life.

Far from being a burden our imperfections in relation to other animals might be regarded as one of the essential characteristics that make us human. In this respect disabled people are the most human of beings. The segregation of disabled people from our non-disabled peers, then, is not only an inhuman event, owing more to the exigencies of the natural world than to social world, but the hiatus between specialist knowledge confined to 'disablement' and public knowledge concerned with 'normality' is no less than the emergence of a profoundly disabling pedagogical barrier in the evolution of human understanding.

The articulation of disabled people's aspirations cannot, in my view, be advanced without reviewing the demise of cerebral flexibility under the authority of rigidly constructed academic and professional disciplines. What might have been gained with the emergence of useful boundaries defining areas of knowledge now inhibits innovation. The 'assessment of needs', for example, has become an essential component in setting the agenda for informed professional interventions for disabled people. While recognising that disabled people do have 'needs' is indeed an historical advance on the view that our impairments render us less than human, the veracity of this view was established by separating disabled people's needs from human aspirations. Our 'needs' then, are attributed to the 'problems' that we face unlike non-disabled people whose needs are expressed by themselves for themselves in defining their own aspirations. Disabled people have others do this for them and in the process have been falsely identified as a uniquely vulnerable group in need of care.

The Berlin Wall that separates information related to disabled people from information concerned with our non-disabled peers is not inadvertent. It marks a specially constructed boundary between two distinctive frames of reference. Authority for this division was provided by the universal acceptability of dividing knowledge into scholarly disciplines and then taking care to keep on one's own side of the wall. What is perhaps not fully appreciated in the community of disabled people is that during the past two decades our agitation about the 'individual' and 'social' models of disability, etc., is not merely an *internal* discussion about the way 'disability' is understood and interventions arranged, but an argument about the nature of all human beings - the essentials of being 'human'. That the discussion about models of disability has been isolated from non-disabled people is a reflection of just how disabling the boundaries of 'normal' knowledge have become. On the one side of the conceptual wall able-bodied people see themselves in terms of 'normality' with a skewed medical view of health and the impossible ambition of providing cradle to grave health services - they have lost sight of their own essential 'vulnerability'; and on the other side disabled people are seen as 'abnormal', 'deviant', 'people with special needs', etc., who must be provided with the equally impossible cradle to grave welfare (care) services.

Able-bodied people have deposited their own natural 'vulnerability', and genuine social dependency, into us as if this was unique to being disabled. Our 'vulnerability' is then seen as an attribute that separates us from the essentially normal - we are not quite human (what I have referred to elsewhere as the 'social death' model of disability; Finkelstein 1991). This transference of vulnerability and consequent dependency into disabled people has not freed able-bodied people from their own dependency upon support systems to ameliorate their essential vulnerability but created a dangerous illusion about the meaning of 'normality'. This is no less than a disabling barrier for able-bodied people which is inhibiting the development of comprehensive knowledge about themselves. In this respect able-bodied people can be truly regarded as disabled; and the status of disabled people is merely a grand reflection of what able-bodied people have been doing to their own lifestyles.

The construction of boundaries around aggregate components of information means that both able-bodied and disabled people are handicapped by discipline.

2. Handicapped by discipline

As far as I am aware prior to the 1975 presentation of the Open University course on 'disability' there were no learning materials in this field which were not located within a discipline area of an academic faculty or as a module in a professional training course. Disability was very much regarded as being *not-able*, as a deviation from the normal. [1] Academic courses which did include the subject generally did so as a diversion from the main discussion and as an interesting consequence of human malfunction due to inherited or acquired physical and mental deficits. When I studied psychology, for example, what little mention there was of disability was raised during our study of neurophysiology when we were introduced to the concept of mental deficits in brain functioning. There were no uncertainties whether it was fitting to confine the notion of disability to the examination of abnormality - disability *was* caused by a pathology of the central nervous system. The accurate measurement of these mental deficits was regarded as a significant contribution that clinical psychologists could make to the scientific diagnosis of a specific disability. The same approach was applied to the identification of different disabilities thought to be caused by deficits of other body organs or limbs. Blindness and deafness, for example, were mentioned in the courses I followed only in terms of problems in visual acuity and auditory loss respectively.

It is important to appreciate that in many respects the person *behind* the possession of a specific deficit was regarded as 'normal'. What rendered him or her 'abnormal' or 'disabled' was the ownership of a particular impairment. Another way of putting this is to say 'disability is a health problem of the able-bodied'. [2] From this point of view the development of a more systematic understanding of disability was initiated through a process of creating boundaries between **two** separate able-bodied concerns about difficulties in living with physical or mental impairments. **Firstly**, what is the nature of the problem that is possessed - the specific deficit, impairment, or disability (when used as a synonym) and how life-threatening is the impairment? **Secondly**, what is the impact of owning an impairment on personal functioning - how can the activities of daily living be effectively managed for or with the impaired 'human being' (ie. able-bodied people)? Disability, then, was interpreted as a general cause for concern and boundaries were established between the two assumed distinct problem areas: the defect and its impact on personal functioning. Within this frame of reference disabled people were regarded as really able-bodied people imprisoned in imperfect bodies. We were seen as separate to, but embedded in, our bodies; in reality separated from ourselves, and the whole 'problem' area was defined by able-bodied people in terms of what they are not, or what they do not want to be. [3]

That disabled people were seen as imprisoned in their bodies, as able-bodied victims of an iniquity, while at the same time owning the bodies that encumber their freedom, not only embraced a contradictory interpretation of 'being disabled' but set impossible lifestyle dilemmas for us. How can we regard ourselves as able-bodied victims of 'something' that is wrong while also being disabled people because the 'something' is part of ourselves; and then at the same time hope to maintain a wholesome personal identity and a fulfilling life? Clearly in this interpretation the whole disability dilemma is internalised in the individual. We are both able-bodied (because our imperfections are regarded as secondary to the 'able' person believed to be inside the defective mind or body) and disabled (because our imperfections are regarded as the primary cause of our 'disabled' experiences). Our imperfections are both secondary and primary! Small wonder, then, that

managing this dichotomous tragedy could only be viewed as a travail uniquely isolated from the everyday life experiences of able-bodied people. In my view the prevailing formal understanding of disability in academic courses and professional training was completed with this **third** boundary between the assumed dilemma of having to come to terms with 'disability' (to 'adjust') and assumed 'normality' of 'able-bodiedness'.

We now have three boundaries demarcating discrete fields for the separation of libraries of information about the nature of disability. [⁴] In my view these are:

- (a) A primary knowledge boundary dividing comprehension of the 'normal' (their needs, goals, ways of developing *supporting* services, etc. - ie. able-bodied lifestyles) from the *special* disability services (their needs, goals, ways of being cared for, etc. - ie. the disabled career).

On the 'disabled' side of this fence two additional boundaries have further dismantled our integrity so that the development of knowledge can always be located in an either / or dilemma between two fields:

- (b) The search for a 'cure' - the health field
- (c) The provision of 'care' - the welfare field

It seems to me that until the emergence of 'disability studies' in the late 1970s knowledge about disabled life, then, was incarcerated in an isolated field where we were endlessly chaperoned by experts in a career without choice between two disability fiats. [⁵]

Disability studies (the study of disabled people's lifestyles and aspirations) clearly could not emerge within the bounds of any discipline that had percolated out of 'normal' academic studies, simply because we had been removed from this arena and all analysis allocated to the disability experts in 'cure or care' (health and welfare) disciplines.

It was also not possible for disability studies to emerge within the bounds of the disciplines concerned with 'cure' because this field was allocated to medicine (and those who play a subordinate role in the professions said to be allied to medicine) where the fundamental intention is to restore 'the impaired' to the greatest approximation of 'normality'. At the very best the frustrated medical approach to curing disability spawned its own peculiar solution in the new discipline of rehabilitation. The history of this approach to intervention, from the perspective of disabled people, I am sure, will be particularly informative because for the most part the pre-requisites for training medical and allied professionals excluded disabled people. Consequently we were prevented from having any real influence on the emergence and development of rehabilitation practice, ethics and philosophy. [⁶] Clearly the boundaries surrounding the fields where the medical and para-medical approaches to disability had free range could never provide fertile ground for disability studies to flower.

So it was in the last field, within the community where established libraries of knowledge (the academic 'disciplines') have their weakest hold over people's behaviour and thinking, that disability studies was to get its opportunity for growth. This is where the skills and knowledge gained from the social experiences of disabled people interacted and clashed with that of non-medical professionals developing their own approach to helping disabled people.

Supporting disabled people in the community has always involved malleable ambiguities. At the one level, if 'highly skilled' professionals cannot do any more in curing an impaired body or mind, and rehabilitation has been successful (maximum 'normality' has been achieved, whatever that might

mean), then it seems reasonable for social responsibility to devolve back into the hands of the family. Of course, responsibility for the majority of disabled people, in any case, never completely fell under the absolute control of qualified practitioners. This meant that considerable power in the guidance of disabled people's lives was in the hands of non-professionals. On another level it is perfectly logical for professional workers located in medical and rehabilitation centres to be driven into the community, following their un-cured patients, when 'care' is the only option left for the possessor of the impairment. [7] The goal in this case was to ensure that disabled people were serviced by skilled professional workers. The need for skilled workers was thought important because the rigid boundary between 'disability' and 'normality' made it impossible for everyday skills used in *supporting* people with abilities (eg. selling bicycles) to be systematically and creatively applied to *caring* for people with disabilities (eg. providing wheelchairs).

The problem here is that the expertise and skills acquired, cultivated and professionalised within the boundary of 'cure' interventions, where 'impairment' is paramount, are migrating into the community where they come into contact with the expertise and understanding that has naturally emerged during lay people's support for their disabled children or peers. At this boundary what is an interaction is also very often a conflict. For the most part in the 1960s and 1970s this has been a 'no-contest' and the natural 'support' provided by the community was systematically eroded and then transformed into 'care' as the professionals gained the upper hand at the apogee of the 'Welfare State'. [8]

It is obvious that the duel between 'care' and 'support' involved a number of players. Apart from the expanding body of professionals the main non-disabled contender for the right to determine the direction of facilities and services in the community were parents of disabled children. Parents, however, are already in a 'care' relationship with their children and, as well-intentioned and responsible adults, want the best for them. For the vast majority this will mean that they want them to be like themselves, as 'normal' as possible. Unlike their disabled children, however, parents actively pursuing the goal of 'assimilation' into mainstream society are likely to be 'people with abilities', 'shoe-bound', aurally conversant or visually informed, etc. There was, therefore, a great deal of common ground between professional and parental interest in developing 'care' services in the 1960s and any differences about the delivery of these services should not confuse us about their mutual affinity. [9] Younghusband et al 1970, for example, says parents of disabled children reported 'The need for relief from the care of a handicapped child at home was the most pressing of all personal and social needs.' (page 44) 'After personal and social needs, education came next in (their) priorities.' (page 52). Parents particularly wanted educational responsibility to move from 'the health to the education authorities'. [10] This move from 'special education treatment' to special education administered by the education authority can be interpreted not merely as a stage on the road to 'inclusive education' but as part of the voyage disability expertise was making from the 'cure' field into the 'care' field. [11] Whatever interpretation is made of this, there was nevertheless in my view, no significant disagreement between parents and disability experts that both care and special education were needed for disabled children. [12]

In the field concerned with 'care', then, there appears to have been little prospect that non-disabled people, drawing only on their own experiences, could be any more creative in developing academic studies concerned with disability than redrafting established wisdom in the 'cure' field. What was needed to open the door to the radically new approach of 'disability studies' was the infusion of ideas directly from the experiences of disabled people.

In the late 1960s and early 1970s the voice of disabled people in the community was expressed through a growing number of organisations each focused around a particular issue. These issues, however, were not freely chosen but arose out of the problems that specific groups of disabled people experienced as they tried to cope with the myriad of barriers in a community designed for able-bodied lifestyles. From the point of view of this paper the most important of these organisations in the late 1960s was the Disablement Income Group (DIG). Its principal concern was that services on the 'care' side of the cure / care fence were under-developed and that a national disability income would help disabled people to integrate by 'compensating for disability'. Mary Greaves, who was the Honorary Director of DIG expressed the problem this way: 'Rehabilitation is composed of three parts - medical, rehabilitation for living and rehabilitation for work. There's a tendency to miss out rehabilitation for living...' (Morris and Butler 1972, page 59). It is clear that disability is seen as a problem in its own right and that thinking was dominated by the model of disability that had developed in isolation of the care sector of the Welfare State. Nevertheless, behind the focus on incomes was the broader goal of support for living in the community (integration). Referring to the Chronically Sick and Disabled Persons Act 1970 (CSDP Act) she is quoted as saying: 'As a disabled person, the importance of this Bill is the underlying philosophy: the integration of the disabled person into society.' (Mary Greaves quoted in Morris and Butler 1972, page 126).

Campbell and Oliver 1996 (page 52) interpret the founding of DIG in terms of disabled people's demand for a share in the 1960s social affluence: 'The idea of a national disability income emerged and was promoted as the way to ensure that disabled people are able to share in the affluence of the time.' It was, then, concern about 'income benefits' as well as broader problems around the issue of access to mainstream society that encouraged many disabled people to join DIG. Stephen Bradshaw, a former Director of the Spinal Injuries Association (SIA) explained: 'When I was first disabled I was very aware of the lack of state benefits. The way disabled people were treated back in 1968 when I came out of hospital was not good, and so I joined DIG straight away, because I thought that was the right way forward to gain basic and obvious things.' (Campbell and Oliver 1996, page 34).

The point I wish to raise here is that in a short period of time DIG grew very rapidly to become a mass organisation of disabled people. Precisely because disabled people unschooled in the perspective of any established disability profession or discipline were able to meet, argue and exchange ideas in DIG made it possible to aspire to a much broader agenda than, as I have argued above, was possible from the perspective of parents caring for disabled children or professional workers either in or out of institutional settings. DIG's concentration of its resources on the single issue of incomes, however, eventually made it unable to translate any wider aspirations for integration into a deeper understanding of the nature of disability. Nevertheless, it increased awareness about the importance of 'integration' and this aim began to challenge the dominance of the more narrow but primary rehabilitation goal of personal 'independence'.

It should be added that in the 1960s and 1970s there were a number of other organisations controlled by disabled people which also contributed to the broader understanding of disability that eventually found its way directly into academic courses; these included the National Federation of the Blind (NFB), Disabled Drivers Association (DDA), Association of Disabled Professionals (ADP), National Union of the Deaf (NUD); as well as the better known organisation for disability: The Royal Association for Disability and Rehabilitation (RADAR), Royal National Institute for the

Blind (RNIB), Royal National Institute for the Deaf (RNID), MENCAP, and the Spastics Society (now SCOPE).

While disabled people in organisations in the community were able to gain expertise and have an impact on professional thinking and eventually academic courses concerned with disability, there was another group of disabled people living in considerable isolation whose views and understanding of disability were almost completely unknown or ignored. 'What was happening is that there were two parallel groups of disabled people. There were those who lived in the community ... They were struggling with one set of issues and they were coping somehow in the community. Then there were those who were in the hospitals on chronic wards, geriatric wards and so on.' (Judy Hunt in Campbell and Oliver 1996 page 29). I will return to the influence of this group's understanding of disability on disability studies later, but I need to conclude this section with a word about the concerns and influence of those who incarcerated disabled people in residential institutions.

There has always been a variety of institutional accommodation for disabled people but it was, in my view, the development of Cheshire Homes that facilitated a very specific analysis of disability that fed into courses aimed at voluntary and professional workers with disabled people. The history of these homes is not pertinent to this discussion, what is important is that they were founded on a very solid charity base by non-professional, non-disabled people and their fundamental concern was 'care'. [¹³ ¹⁴] Disabled people were uncritically accepted as a problem, for the most part unemployable and incapable of managing much of the activities of daily living (the tasks of 'normal' life) solely because we are disabled. We were essentially regarded as incapable of functioning in ordinary life and consequently invisible to, and conceptually separate from, the public. 'The problem of the incurably sick tends to be hidden from the public view and so to many people it doesn't exist.' (1963 Foreword by The Duke of Edinburgh in Russell 1980 page 7).

The 'problem', which appeared to need no clarification for the founders of Cheshire Homes, could be expressed as: 'who will care for the disabled?' The question not asked was: 'why is there no appropriate 'support' system for disabled people in the community, similar to the elaborate public utilities that able-bodied people share between themselves?' It was, however, not only the failure to question the advantage of incarcerating us in institutions that is extraordinary in the light of the resources being committed to the Cheshire enterprise but the level of ignorance that was happily tolerated. When, in the early 1960s, questions were raised about the number of Homes that were 'needed' Russell (1980 page 17) says: 'I realized for the first time that beneath our work was a bedrock of ignorance - ignorance of the basic facts, ignorance of the number of chronic sick in the modern world.'. To this I would add 'ignorance about the nature of disability'. It was ignorance, then, that characterised the whole residential institutional approach and this ignorance was tolerated because an intellectual boundary had been placed around the world of disability preventing critical interest from non-disability academics and researchers. [¹⁵] Ignorance also made it also virtually impossible for the protest voice of disabled people to be heard at this time. [¹⁶]

Ignorance about the nature of disability, too, played an important role in facilitating a notorious oppressive piece of social science research targeted on institutions. In 1972 Miller and Gwynne, publicly admitting their confusion about the dynamic situation of disabled people, concluded that the function of the residential institution was to provide the 'socially dead' with transitional care until natural death occurred. [¹⁷] To them there were two basic issues: how to ensure that this process from social to actual death was extended as long as feasible and supported in the most humane way possible, and what education and training was needed to assist staff cope with this stressful line of

work. [18] At a time when there had been several scandals about institutional 'care' for people with mental illness and learning disability and the closure of large institutions was on the agenda, Miller and Gwnne's publication of their research was eagerly fed into education and training courses for care workers.

In the early 1970s work began on the first Open University (OU) course wholly concerned with 'disability'. It entered its long production period in an overwhelming cultural climate where academic boundaries confined the study of disability to an esoteric field peopled by a tiny minority of unchallenged experts. Out in the real world those working with disabled people were devoutly separated into cure or care concerns; practice in the latter being informed by historical assumptions without even the pretence of an underlying scholarship. The migration of the 'cure' experts and 'professional expertise' into the community, where their practice was re-labelled 'care' while their assumptions remained unchanged, had begun in earnest.

The publication reporting the outcome of the London Borough of 'Lambeth studies of disablement', which were planned in 1977, captures the mood of this decade at the time: 'It is now widely accepted that the balance of health and social care for people with disability should shift from being institutional or residential to care in the community. ... a complete picture of the burden of chronic illness on the life of this section of the community (disabled adults aged 16-75 living in their own homes) demands a socio-medical definition of disablement.' (Patrick and Peach 1989 Preface p. v). The claim to continuing medical control over the lives of disabled people in the community was unashamedly pursued.

For:

'Disablement is a major social problem. It affects not only the people who are disabled, but also their families and friends, their health and social care providers, and all members of their communities.' (Patrick and Peach 1989 p. 1).

We should read:

Disablement is a major social problem. It infects not only the people who are disabled, but also their families and friends, their health and social care providers, and all members of their communities.

3. The Handicapped Person in the Community

The OU contribution to 'disability studies', then, began in an environment of change with the medical model of disability about to breach the wall between institution and community, suppressing the natural evolution of social support and systematically replacing this with its administrative compliment: 'care'. This was a period of new, but not overwhelming, instability in the informed opinion about the nature of disability. Different interpretations began contending for hegemony over the direction of interventions and services. On the whole, however, there was no dispute between the professions and voluntary workers that disabled people need looking after and special services; disagreements amounted to no more than variations on the same theme.

The university's response to the unfolding change in the world of disability was also a product of its time and we need to bear this in mind when we consider what made its first course in this field uniquely creative. The OU was not only new, having just started teaching in 1971, but there were no entry requirements apart from being over 18 years, living in the UK and being competent in English. Courses were to be presented at a distance with a minimum of face to face contact at local

tutorials and summer schools. Individual tuition was to be conducted via a system of tutor marked assignments carried out by part-time tutors. A significant concern, and part of its Charter, was to ensure *all* multi-media learning materials required for the completion of a course were available to each student in their own homes. The invisibility of disability behind its *special* wall meant, of course, that the OU approach to higher education was not fully appreciated as a formula for aspiring disabled students. Having been banned from traditional universities because poor secondary education deprived them of academic entry qualifications or because campuses were inaccessible the Open University gave disabled people a second chance. Courses, however, were produced for the shoe-bound, aurally conversant and visually informed student with ability and it became necessary to set up a disabled students office very early in the university's life. The approach was to make special provision for disabled students.

Being a new university with an untried approach to teaching and considerable scepticism from academics in traditional institutions an early concern was to establish the credibility of the OU courses and degrees. It was also necessary to create a system of course production which enabled an appropriate input from academics, course co-ordinators, educational technologist, editors, television and radio producers (the BBC input), course production planners and administrators, etc., to ensure standards and consistency in academic content and the viability of the teaching approach. The course team became the basic unit of course production and a melting pot for the exchange of ideas. It was also accepted that the academic input from this teamwork approach could be augmented by 'consultative conferences' in order to access suggestions and opinions from non-OU experts in a proposed new course.

In the early 1970s the changing climate in 'dealing with disability', discussed above, increased interest in the move towards integrated education and the Faculty of Educational Studies began considering the preparation of a course on special education. At the time the OU focus was on undergraduate degrees and the viability of distance learning for students in the professions who wanted to improve their practice by studying upgrading courses was not a priority. The Education Faculty, however, always maintained an interest in the development of teachers and supported the production of post-experience courses. A Post-Experience Courses Sub-Committee, managed by a Director, was created to support a small number of courses on a range of topics outside the undergraduate programme area. Phillip Williams, from the Faculty was appointed Chairman of the proposed new course located in the post-experience courses programme and a course team brought together. This meant the new course had crossed a very significant disabling boundary. It was no longer to be constrained by a single faculty interest or bounded by an established disability discipline.

At this time Vida Carver was a Staff Tutor in the Faculty of Social Sciences in the London Region and had played a leading role in making courses accessible to students with hearing impairments. This was her speciality having joined the OU from a research project with the Central Council for Education and Training in Social Work. Dr Carver not only had worked 'out there' with disabled people, been engaged in the practical side of making courses accessible, but also knew leading disabled people personally: she was particularly friendly with Mary Greaves from DIG (mentioned earlier). Dr Carver was seconded to the course and immediately brought the wider issues I have discussed above in some detail into the melting pot of ideas that the course team had to consider in deciding the nature of the new course. Dr Carver was a most persuasive advocate for change in the way issues in disability were studied and under her influence it was decided to radically broaden the scope of the new course. In the terms of the time the new course was to be The Handicapped

Person in the Community. It was to be topic based, with only one workbook concerned with special education, and the main focus on improving professional practice with disabled people living in the community.

Very early in the course production cycle a consultative process took place involving communication with a large number of individuals who had been identified as interested in the field. A Consultative Conference confirmed the broader topic based approach as an important contribution to the shifting emphasis on developing services for disabled people in the community. Care was taken to include leading representatives from all the main professions with a concern in 'disability' as well as some of the few disabled people researching in the subject or active in disability related organisations. [19]

It is my view that in the course team forum, outside the boundaries of established disability disciplines and traditional faculty structures, in a new and innovative pedagogic institution, in a climate of shifting emphasis from the cure to care fields and in the context of general economic affluence, a new academic approach to disability started to emerge. [20] This is clear from the Handicapped Person in the Community course aims published in 1975 for its first presentation year: [21]

The aim of the course is to help you to improve your professional and social skills in order to assist handicapped people to achieve maximum autonomy.

The well-established rehabilitation goal of 'independence' has been replaced by 'autonomy' and interpreted broadly in terms of civic rights [22] but with still some uncertainty about the meaning of a successful lifestyle for disabled people. The aims continue:

... It will call on you to examine your professional role and ideology and will encourage you to adopt an interprofessional approach to problems.

While disability is still contextualised in terms of problems discipline boundaries are slightly breached with the promotion of an *interprofessional* approach rather than the rehabilitation concept of *multi-professional* teams. More importantly, students were encouraged to question the prevailing ideology. The aims conclude with the promotion of co-operation with:

... other workers, with disabled people and with the wider community.

This significantly broader approach to the academic study of disability is most clear in the titles of various course components. *Difference and the problem of developing a handicapped identity* was the first unit in the course. This raised the issue of identity rather than taking for granted medical assumptions about the centrality of 'normality' in disabled people's lives and the need to 'adjust' when this was not fully attainable. *The medical approach to handicap* was only one unit in sixteen alongside traditional boundaries between workbook units concerned with *Hearing impairment ...*, *Visual handicap ...*, *Aids for the physically handicapped ...*, and *The social integration of mentally handicapped people ...*

Boundaries, however, were challenged with more global approaches to intervention. These were presented as relevant to all workers and all groups of disabled people. The 'behavioural' *Goal-setting* workbook was given a prominent place in the course, rather than professional obsession with assessment of needs. *Anticipating needs and matching services* was the title of a workbook, for example, rather than 'the assessment of needs for services'. Units on personal income and costs of care raised issues that were simply absent in professional courses for therapists, teachers and medical workers with disabled people. Much of this material was entirely new and generated in production of the course. For the first time, too, disabled people contributed as

colleagues, rather than as case studies, in the making of the course. Peter Large, active in DIG and the campaign for anti-discrimination legislation, Brian Gritt, a social services liaison officer, Fred Reid, President of the National Federation of the Blind, and James Woodward, formerly a research officer at Lancaster University, amongst others wrote course units and were contracted as consultants to the course team.

The varied professional interests and confused meaning of disability during the systematic migration of service ideology from the institution to the community was reflected in the course. Eric Miller was engaged to prepare a Unit based upon his research with Gwynne on residential homes (mentioned earlier). The focus in this workbook was on the psychological problems faced by practitioners working with the tragedy of disabled people. In this case improving professional practice meant assisting workers adjust to their emotionally disturbing jobs. This was countered by a Reader paper on the Swedish Fokus project which aimed at enabling all disabled people live in the community with appropriate support. [23]

The broad sweep of the course is summarised in the Introduction for the course Reader:

'This Reader has been designed to meet a demand for information, on the situation, services and needs of handicapped people, required in training courses that are generic in either or both of the following ways: (a) across the range of various forms of handicap experienced by the population of Britain, (b) across the range of different professions, agencies and persons involved with handicapped people.' (Boswell 1974, page 1) [24]

Just over 1,200 students, working in all the professions with a concern in the disability field, voluntary workers and disabled people from all areas in the country studied the course in its first year. Its influence was widespread creating waves of unease amongst those working to established disability models, giving confidence to practitioners and service users who were looking for a more comprehensive approach to disability issues, and seeding ideas for those who questioned prevailing assumptions about disability and who wanted to pursue the academic study of disability in its own right. The latter was to flower in UK as Disability Studies. What was missing in the Handicapped Person in the Community course was the unbounded ideas of disabled people, freed from academic and professional disciplines. This required a shift from the individual and biographical approach, which confined disabled people to a case history role in the career of disability professionals, to a social approach relocating the problem of disability to the disabling society and countering the individual model of disability concurrently relocating from the cure setting into care in the community.

4. The Disabling Society

The minimal involvement of disabled people in the production of the first OU course in, what was to eventually become, the Disability Studies Programme Area in the School of Health and Social Welfare was not surprising. Prejudice against disabled people prevented access to employment [25] and the prevailing fiat dictated the exclusion of disabled people from this field because of alleged inability to be objective about themselves and their situation. [26] There were also very few disabled people at that time with the qualifications to contribute to university level courses as academics. In this light what is surprising is just how successful the OU course team was in resisting pressure and in engaging disabled people in the course production and presentation.

I became involved with The Handicapped Person in the Community course in 1975 as a part-time tutor during its first presentation year, having missed the opportunity to contribute to the course production. Although I had qualified as a Clinical Psychologist with the original intention of working as a counsellor for disabled people in a rehabilitation centre I had been unable to obtain a post in this

specific area of psychology. The Open University, then, not only gave me the opportunity to work in the field that I wanted to but with Vida Carver's encouragement positively recruited me. At the time I was heavily engaged in a number of disability organisations, principally the Union of the Physically Impaired Against Segregation (UPIAS) where we had developed the social interpretation of disability [²⁷], and we had developed a healthy scepticism towards disability related research and courses. On the other hand we had agreed that it was essential to find ways of engaging disabled people in disability affairs across the whole range of human endeavour, constantly trying to break down the boundaries that kept us isolated from mainstream society, maintained professional control over our lives and stunted a deeper understanding of human nature. The OU presented us with the opportunity to push a wheel-in (gain a toe-hold in) the academic world where we could hope to bring our own viewpoint into the arena dominated by the medical and administrative models of disability.

The Handicapped Person in the Community course was presented unchanged from 1975 until 1980. During this period the voice of disabled people was growing more confident. New organisations of disabled people, such as the Spinal Injuries Association (SIA) and the National Union of the Deaf (NUD), for example, were able to support outstanding spokespeople in Stephen Bradshaw and Paddy Ladd respectively, who argued the perspective of their groups with increasing effect (see Campbell and Oliver 1996 for a fuller discussion of this period). In Derbyshire Ken Davis and Maggie Hines had started setting up the Centre for Integrated Living (CIL) and their pioneering Grove Road housing project (Davis 1981); in Manchester Ken Lumb played a key role in supporting the first research project based upon the social model of disability (Finlay 1978); and Dick Leaman, in the London Borough of Lambeth had started working towards their CIL.

I mention these developments because as I became employed full time at the OU in 1976 and more settled into the job I was able to refer to these exciting projects in the course updating material and regional 'day schools'. It was a matter of policy at that time for me to attend a few day schools each year and I made a point, whenever possible, of circulating copies of disabled people's writing and talking about the projects that were engaging their attention. These contacts, my involvement with my own tutorial groups, assignment monitoring and examination marking, not only provided a vast source of national feedback on what was happening at the local level but highlighted the problem of structural intransigence in the face of change. It became clear that in the world of 'disability' the 'market' should be respected but never allowed to dictate academic judgements about appropriate courses in a field or their erudite content. To allow this to happen would be to concede academic domination to the prevailing model of disability rather than to promote the model that most accurately seems to accord with the facts.

Increased familiarity with the course and exchange of views with those who had studied or reviewed the material helped clarify both its strengths and weaknesses. The principle problem, already mentioned, was the limited input that had originally been possible from disabled people - in particular the debate about different models of disability. I had discussed this with Paul Hunt (who had played the leading role in founding UPIAS and contributed to the development of the social model of disability) and in November 1976 he wrote to the course team suggesting changes when course materials were updated. Firstly, he drew attention to the Margot Jefferys and Amelia Harris definitions reproduced in the course and commented:

... little attempt is made to examine these definitions critically, to discuss their underlying assumptions and inconsistencies, or to put forward better definitions in their place. ... surely the crucial defect in the definitions quoted should have been pointed out: that Margot Jefferys and

Amelia Harris fail to break with the traditional view of disability as an essentially individual condition which causes certain personal and social effects.

In his conclusion he praised the course for breaking through the boundaries which separated knowledge about disability into independent fields and hoped that this would be taken further by introducing students to the social interpretation of disability:

Finally, it seems to me that part of the usefulness of the Course you have developed is that it collects together what is on the whole the more progressive thinking and practice in the field, and I hope that you will therefore be able to acquaint your students with the alternative social approach to the question of definitions.

Vida Carver replied with the view

that the differences between us are at the level of language usage ...

and defended the definitions used in the course with the view:

The purpose of a definition is, for me, no more and no less than a statement, made in the interest of clarity, of the way in which a term will be used. ... Troubles begin when we try to incorporate attitudes or 'philosophies' into definitions ...

But she expressed full support for the concern behind Paul Hunt's letter:

I have no quarrel with the sentiments that lie behind your definition of disability - indeed it was our hope that the whole course was an elaboration of those sentiments.

This correspondence was important because it helped clarify the pace for the introduction of disability studies into the academic world. This, I knew, would begin in earnest when we were able to start remaking *The Handicapped Person in the Community* course. I was fortunate in being able to engage Mike Oliver in this process. He had been recruited as an OU part-time tutor at an early stage in the presentation of the first course [²⁸] and immediately played a constructive role in disseminating ideas from the course as well as developing his own critique of the original materials. In the meantime we were collecting regular feedback from each year's presentation and quite a wide range of unsolicited correspondence from people who had seen our BBC television broadcasts, heard our radio programmes, read our text books or *Reader*, or reviewed the workbooks.

As the first comprehensive course in the field with a large yearly student intake there was considerable awareness about the course in what was, and still is, despite the large number of non-qualified people involved, an isolated and relatively small body of academics, researchers and professionals. The course was widely discussed in this circle, praised and criticised. For the most part this feedback was exceptionally positive. The most frequent comment was that we had omitted an element in the already overloaded course that was championed by a correspondent. The greatest controversy centred around the behavioural goal setting approach. For some this was seen as a tool in breaking down tasks into clear logical steps to be systematically achieved by disabled people. To others this was a controversial method of controlling disabled people so that they could be moulded according to the dictates of non-disabled practitioners. Most comments from disabled people were highly critical of the workbook by Eric Miller on problems in working with disabled people, but positive comments were also received from workers who regarded the discussion helpful in addressing their own uncertainties and prejudices about disability.

In the first two years of its presentation *The Handicapped Person in the Community* course was only available in the post-experience courses programme, but after that it was also open to undergraduate students. This had an effect on the student profile, although this was not as significant as might have been expected. In the early years a large number of students had come from the

teaching professions. Later on professional and voluntary workers in the community had become the dominant student groups. There were always a small number of disabled students, mostly following the course out of interest, but with a few who were trying to find a path into employment in this area. In the undergraduate programme we also attracted a small number of students with no obvious interest in the field. The medical profession, however, was always under-represented, given their role in the lives of disabled people and for the most part paid little attention to the course.

There had been some input from medical consultants when the original course was planned and a Unit on the medical approach to disability was included. In taking into consideration all the above feedback, opinions from respected leading disabled people and professionals and caution in over-reaching the interest of practitioners who had to work within structures suffused with enduring assumptions and models of disability it was decided that the course would be remade over three years, replacing a few units at a time while retaining the basic structure and reworking the topics already within the course. The medical Unit was to be retained although remade along with the rest of the course.

It is appropriate to conclude this section with an indication of the kind of difficulties faced by the original course team when it embarked on the singular task of producing a course wholly concerned with disability but not located or dominated by an established discipline or professional approach to disability.

As part of the ongoing feedback prior to finally deciding the structure and content of a replacement course, if any, student reviews are commonly undertaken. These not only provide a new course team with comments about an old course but possible directions for the remake. It so happened that a medical consultant made contact with a few students who had participated in the survey and became alarmed that a course addressing disability issues was attracting large numbers of students without their blessing and contribution. In responding to a query about the proposed new course we had sent some current publicity material and an indication of the possible replacement. I had decided that if the consultant was conversant with the contemporary debate about the nature of disability and the implications for future service development then there might be interest in using materials from our course in their rehabilitation studies. This, I thought, might help the development of disability studies. A hilarious exchange of concerns then took place between us:

One aspect of your letter gives me great cause for concern, because the whole reason for our interest in this course was that our association is deeply involved in work with handicapped people and we very much wanted to be in a position to look at future plans for development of the course with you to represent the medical professional angle. ... our impression was that a number of colleagues in the remedial professions felt that the course was showing highly sociological bias, but we wanted to know whether this was a criticism of only a few or something that was felt by many people. We would like to offer help in considering some of the medical aspects of the subject ...

I welcomed the possibility of constructive criticism and sent some course materials for comment, indicating at the same time in the light of our vastly greater student numbers and experience in the field we would be willing to review their course and perhaps provide them with help too:

I greatly appreciate your concern about our course but would not agree that the sociological understanding we encourage amounts to either a criticism of the course or a bias. I value your offer of help on the medical aspects of the subject and would be interested to receive your comments on the course content ... On the basis of your comments I am sure we can mutually exchange ideas about courses on handicap and perhaps collaborate on future plans. ... I would be very interested to have details about the courses you teach and perhaps the results of any

research carried out on your students. ... I would be very willing to help from our experience of teaching a multi-disciplinary course on handicap.

With comical insensitivity the exchange was continued:

I think the thing we feel about this course ... is that there are some very important practical and vocational aspects to any person working with handicapped people. It is of great concern to us what people are taught about handicapped people, and we do not accept that this is purely a subject for academic sociological study, we do believe that there are aspects of any study of handicap which have immensely practical and medical importance which is why we feel that we ought to be informed about training courses.

In response I once again politely repeated my offer to help them with their course:

I am in considerable sympathy with your concern about the importance of the practical and medical implications of any study on aspects of the situation experienced by disabled people. I do not see this total situation is best expressed through 'purely' academic sociology or 'purely' practical medicine. For this reason I believe the course correctly encourages an inter-professional team approach without unduly emphasising any one aspect of the situation in which professional workers may come into the lives of disabled people. ... I am very interested in the content of courses you present, which involve handicapped people, and look forward to sending you my comments on receipt of these details.

Of course we never heard from this source again. I suspect that it was just beyond their ability to comment on our high quality and comprehensive multi-media learning materials and sending an outline of their courses would have been an embarrassment.

The punch line in this frustrated demonstration of rehabilitation imperialism is that I had met two remedial therapists, former students of the good doctor, at a conference arranged by disabled people who expressed considerable dissatisfaction with the consultant's course and teaching. Their claim was that the medical emphasis was rather misplaced in the real and practical world of the community.

5. Conclusion: mainstreaming the vulnerable

A new course team began rewriting the materials for the first Units to be replaced in the 1980 presentation. All the components were replaced by 1982 and although the course retained its old title it was in fact entirely new and, in my opinion, could now be properly identified as a course in Disability Studies. When the team was assembled we engaged in a number of brain-storming sessions, trying to ensure that the new ideas emerging from the community of disabled people were considered alongside the more progressive views coming from the established professions and voluntary bodies.

Amongst the several external consultants involved in the new course was Mike Oliver. I was to rely heavily on his input because the boundary isolating disabled from non-disabled people made it difficult for even the most sympathetic academics familiar with the field to get a full grasp of the new ideas in the short space of time leading up to actually preparing course components. The transformation of the original Handicapped Person in the Community course for entry into Disability Studies was a remarkable learning experience for us all. [²⁹]

The first Workbook to be replaced was, of course, concerned with the work Miller and Gwynne had carried out on residential care that had so offended the people who had invited them to conduct the research in the first place. The associated television programmes and set book were also replaced and in a very real way the removal of these materials marked a turning point in the development of disability studies. The driving force behind course content now came into the hands

of disabled people and the concerns of service providers were not ignored but interpreted in this context. We also made an effort to challenge traditional ways of dividing disability up into discussion areas. Rather than considering blindness and deafness, for example, we merged this discussion and looked at barriers to communication. The significance of physical impairment was studied in relation to disabling barriers and the means to overcome these. Learning disability was located in a consideration of personal relationships and the support society is prepared to make available. Considerable space was given to reworking personal, professional and public assumptions about disability. In keeping with the focus of all the Health and Social Welfare courses at the OU the emphasis was on improving services, working with disabled people and thinking through appropriate services rather than revitalising existing approaches and professionalism.

The new course received a mixed reception. Many workers found the materials invigorating and rich in ideas, but difficult to translate into practical approaches in service settings totally directed by the individual, medical and administrative models of disability. Over a period of time, however, there is no doubt that the course ideas began to penetrate the wider scene. A substantial reason for this is because the disability movement began to have a much more substantial impact on challenging the comfortable assumptions that had for so long fed the direction of servicing disabled people. There was a powerful concord between the OU course and the groundswell of opinion emanating from the national and international disability movement.

In 1989 work began on the final version of this disability course. It was to be produced in modular form with the completed course called *The Disabling Society*. There was much greater input from leading disabled people who had played a role in reshaping our understanding of disability. The concern about developing appropriate services was maintained together with an enhanced role for disabled people as the new Centres for Integrated Living (CILs) were set up by disabled people and began providing some services. The separation between purchasing and providing services had perhaps opened up new possibilities for service development and at the same time direct payments to disabled people and civil rights legislation finally completed the long haul from institutional approaches to community based approaches.

Although the introduction of 'community care' can be regarded as an important development it has, as I have argued above, been the main vehicle for transporting traditional cultures of intervening in the lives of disabled people into the community. While there are many reasons for the decline in the number of students following the introduction of *The Disabling Society* course, it is my view that 'community care' has been the greatest contributor. I believe that 'care in the community' can easily come to be seen as the logical home for 'disability studies'. But 'care' is a provision that 'mainstream society' makes for the support of 'vulnerable groups'. By assigning disability to what may easily become a new academic category disability is at the same time being firmly confined behind the narrow walls of specialist expertise that is regarded necessary to cope with vulnerable groups. In a very real sense, the whole history of 'disability studies' has been a record of trying to break out of this imprisonment.

'Care', as a new academic category would not owe its emergence to the unfolding of new levels of knowledge about vulnerable groups, but simply be a response to a growing student market purely driven by legislation. Legislation, as we know, is the product of a diverse range of political pressures. Care, then, as a new academic 'discipline' for course development, and the location of disability studies within this, would have no academic life independent of political fashion. While, as I suggested earlier, we must respect the market for course development, the vitality of disability

studies (and arguably the study of all 'vulnerable groups') requires innovative relocation within mainstream science and academic disciplines. This could help counter the illusion that the provision of community care is an appropriate response to the social model of disability. In my view this new form of intervention is nothing more, nor less, than the old separation of support systems for disabled people from the support systems that non-disabled people enjoy under a new name. It is a formula for trying to revitalise moribund professionalism at a time when, more than ever, we should be discussing the dismantling of a fragmenting health and welfare service and replacing this with mainstream National Medical Services and services concerned with supporting people achieve their lifestyle aspirations. We should be debating the unpacking of current professions in order to identify those skills which may be reassembled in more appropriate professional configurations for the 21st Century.

If there was a compelling lesson from over twenty years developing disability studies at the Open University and introducing over 8,000 students to a different way of understanding human behaviour it is that we should be looking at ways of breaching boundaries. Dismantling the faculty system and making topic based course across the disciplines, for a start, might bring back some of the innovative teaching that first characterised the OU. Disability Studies, in my view, can play an important role in drawing attention to these issues. Failure to do so is likely to result in the new field of disability studies just becoming one amongst many where an academic elite avoids the opportunity of our time.

NOTES

¹ The 1921 Education Act for example 'specified five types of defective children: the blind, the deaf, the physically defective, the mentally defective and the epileptic.' (Younghusband 1970, page 205).

² Sadly in some professions little has changed. Professor Marie Johnston gave the 1995 President's Award Lecture at the British Psychological Society's Annual Conference. In what can only be politely described as an embarrassing presentation on 'Models of Disability', however, she does not make a **single** reference to the growing field of disability studies in the UK where there is vibrant discussion amongst disabled activists, researchers, academics, practitioners and their able-bodied colleagues on this subject. In her paper you will still find prehistoric comments like 'Physical disability is a major health problem.' and quaint notions of identifying degrees of disability with the suggestion that 'those who cannot get out of bed have a worse level of disability ...' (Johnston 1996, p.205)

The World Health Organisation, of course, demonstrated the same innocence much earlier when it produced an inventory of deficits which may be selected in dressing up the *entire* identity of each individual disabled person for display in the 'context of health' (WHO 1980).

³ The essential spirit behind this construction of 'disabled people' is most perfectly captured in the term 'people with disabilities'. Here, the word 'people', does not have to be defined simply because it is already culturally appropriated by the dominant group that characterises the people whom, in contrast, we ought to refer to both in legislation and everyday language as 'people with abilities' ('normal' white, able-bodied, working-age, males).

⁴ Perhaps, then, in pursuing their analysis of 'disability' from a purely able-bodied perspective it is no accident that the World Health Organisation's classification of impairment, disability and handicap has ended up being no more than the fossilised remains of the three primitive boundaries which I have argued in this paper informed earlier assumptions about the nature of disability. (WHO 1980).

⁵ The fact that 'people with abilities' did not question their own unhealthy 'cradle to grave' career in a welfare state that sanctions the hegemony of health and welfare professionals shows just how much power can

be drained from the 'normal' when a boundary isolates them from their disabled peers whose basic lifestyle interests must be, in the end, not to concede such control to others.

⁶ This argument is most avidly demonstrated in the development of 'conductive education' in the Peto Andreas Institute in Hungary where the adaptation of schools to admit children with cerebral palsy was neglected in favour of confining these children to a special environment where round the clock intervention strives to make them as normal as possible. It is here, in this approach, that the goal of 'normality' is pursued to absurdity and informed by a complete absence of the views of disabled people. (see Oliver 1989, French 1994, Finkelstein 1990, for a more detailed critique of this approach).

⁷ The most perfect example of this migration (medicalisation of the natural community based support networks for disabled people) is found in the concept of 'community-based rehabilitation'. For a discussion on the different approaches to community based interventions see Lysack and Kaufert 1994.

⁸ Although the momentum for professionalising community based support systems for disabled people continued for some time after 1970, in my view The Chronically Sick and Disabled Persons Act (1970) marked the end of the Welfare State's expanding institutionalised administrative control over disabled people. This Act gave an enormous boost to qualified workers moving from hospital and rehabilitation units to the social services. On relocating in the community the professional culture, acquired in isolation from the community, was given an opportunity to infect the wider lay culture involved in supporting and caring for disabled people in the community. The professionalisation of *support* eventually surfaced some twenty years later like a boil in the form of *community care* in the National Health Service and Community Care Act 1990. Thereafter the Welfare State has fragmented at an ever increasing pace, leaving behind the *community care* scab as an irritant itch in the body politic of the disabled community.

⁹ What parents experience as a problem does not appear to be 'care' as such, but that there is not enough care, the care is misdirected or badly managed, or they feel that not enough effort has been made to find a 'cure' for their disabled child (hence the appeal of conductive education at the Peto Institute).

¹⁰ "What is vitally important to remember is that up to 1971 special schools were under the control of the Department of Health and Social Services. Many were known as Junior Training Centres. Now while the above reasons for such provision are depicted in positive terms and were influenced by humanitarian concerns, the dominant assumptions and perspectives influencing both policy and practice were medical and psychological.' (Barton 1995, p. 29)

¹¹ Anderson's 1973 research on integrated education is a good read providing timely insight into general parental subservience to 'expert' opinion in the management and 'treatment' of disabled people, even when lay opinion started to find its own voice as services began their migration into the community.

¹² Special education should not be confused with special schooling. The latter tended to be disliked by the majority of parents (Anderson 1973 p. 76). With the ascendancy of professional expertise in the community the concept of 'special needs' has progressively become the preferred generic term for sanctioning all forms of intervention directed at disabled people. This is not a new approach but simply the medical and individual models dressed in new clothes for their outing into the community.

Mike Oliver 1988 p. 20. puts it this way: 'There is also a sense in which the history of special education can be seen as a social construction, or rather, a social reconstruction of the problem. From the introduction of categories such as "idiots and imbeciles" in early legislation, through the medical categories of 1944, to special educational needs in 1981, it could be argued that the labels have changed; the underlying reality of an educational system unable or unwilling to meet the needs of all children remains the same.'

¹³ For an indulgent history of the Cheshire Homes see Russell 1963.

¹⁴ There are a large number of criticisms of the Cheshire Homes, for example: Finkelstein 1991, Hunt 1981, Morris 1993, Oliver 1990.

¹⁵ It was more than tolerated; after all their ignorance was rewarded with public acclaim from other non-disabled people for their good works - Cheshire was made a Lord for systematically incarcerating disabled people.

¹⁶ 'Disabled people have become increasingly critical of the role of professionals in their lives, in that such encounters have been viewed as essentially demeaning and oppressive. Part of their criticism is that they have a voice but it is not being listened to, and that their perspective is under-valued. The concerns they raise are

fundamental and include the extent to which they control their own bodies and lives. They demand the opportunity to make their own decisions and exercise choices, and thus the question of empowerment is central to their objectives.' Barton 1989 page 1.

¹⁷ 'Here ('residential institutions for cripples') we enter a jungle of stereotyped expectations and prejudices in which it is difficult to distinguish reason from rationalization, fact from fantasy. As we tried to show in the Introduction, we ourselves, are none to certain of our own orientation in this jungle.' Miller and Gwynne 1972, page 41.

¹⁸ The researchers' assumptions, methodology and outcomes have been repeatedly criticised by disabled people, including those involved in inviting them to conduct their research in the first place. See for example, Hunt 1981, Morris 1993 p.18, Oliver 1990 p. 9, Oliver 1983 p. 89.

¹⁹ There were, of course, some established professionals who recorded their disquiet about the proposed course, alleging gaps in coverage, incorrect emphasis in the course focus, even undue influence of disabled people on course content, etc. The course team response was to point out that although '... some of the units will be concerned with special education, ... the course as a whole has a much broader target.' and that '... the purpose of the course, which is generic ... deals primarily with the social aspects of disability, and for this reason should be of value to people in a number of related professions, but it is in no sense a professional training.'

²⁰ As early as February 1975, the first year of presentation of the new course, Vida Carver was proposing that the OU start production of a 'Diploma in Disablement Studies'.

²¹ Introduction and Guide to the Course (1975). P853 The Handicapped Person in the Community, page 4. The Open University.

²² ... We live in what are, hopefully, exciting times for the disabled in Britain ... We have no doubt that the greatest achievements will be those that permit handicapped people and their families to decide what they will do, where they will go and what they will work at. It is only by attaining this position of autonomy that they will be able to go their own way like other citizens ... The battle that disabled people are now waging for themselves is ... for employment, income maintenance, health and education. Its target is the 'public burden model of welfare' that Richard Titmuss exposed in ... the 'Welfare State and Welfare Society'. What they seek are their civic rights ... (Boswell 1974, page 2)

²³ 'The only way of achieving the right attitude to the disabled is to accept him as a collaborator and fellow member of the community; a man who can take full responsibility for his life and actions.' Brattgard 1974, page 7

²⁴ Phillip Williams, the Course Team Chairman in 1974 put it this way, in reply to a question about the limited reference to speech therapy: "The course is planned as an introduction to the study of handicap. It is for this reason that only four of the sixteen units are concerned with specific handicapping conditions. The remaining 12 units aim to study problems of handicap which are of general applicability irrespective of the nature of the handicap itself.'

²⁵ Very early in 1974 as the course got well under way Vida Carver, with the full backing of other members of the course team, wanted the Post-Experience Courses Unit to engage a disabled secretary. This was vigorously opposed by the then Director of the Unit who foresaw 'difficulties ... employing a handicapped secretary...' and was 'firmly of the opinion that a handicapped person would present a very big challenge to the typing services of the whole unit ...'

²⁶ Letter to the course team in 1974: 'I realise that you have handicapped people advising you and acting as tutors, and also contributing to course programmes, but on the whole, these are the success stories, the intellectually gifted and probably socially competent people, and I have found from experience that although the contribution of such people to society is valuable, there is a tendency for them to judge the problems of all handicapped people in the same way as the ones which form this minority group.'

²⁷ UPIAS started with a letter from Paul Hunt in the GUARDIAN in September 1972 and this was immediately followed with a lively discussion amongst a small group of disabled people in which the social interpretation of disability was clarified. By the end of 1974 I had consolidated my own thoughts on the subject and began popularising this approach (Finkelstein 1975a and 1975b). The official UPIAS view was published a year later (UPIAS 1976) having been mainly written by Paul Hunt, Dick Leaman, myself and contributions from Ken Davis with comments from many other members.

²⁸ '... as a postgraduate student with a young family to support, one of the few occasions when disability became a positive advantage was when the Open University began looking for course tutors for its new disability course.' (Oliver 1996 page 8)

²⁹ Mike Oliver comments on this in a biographical note as follows: 'These changes are also a part of my own personal biography for, in one way or another, I have been involved in these courses almost since their inception, initially as a course tutor and then as a member of the course teams responsible for the revision and production of the new course. Changes in my own thinking about disability were both reflected in and influenced by changes in the Open University courses.' Oliver 1993

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