

CHAPTER 5 (In 'Disability Studies: Past Present and Future' edited by Len Barton and Mike Oliver (1997); Leeds: The Disability Press, pp. 78 - 90).

'Growing Pains' Disability Politics The Journey Explained and Described

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INTRODUCTION

This paper will attempt to shed some light on the complex and often quite hidden political process of the Disabled Persons Movement over the past 30 years. Although the first stirrings of political 'protest' from organisations of disabled people go as far back as the late 19th century, this chapter will concentrate on the Movement from a time when impairment boundaries were crossed and a united approach to social oppression took off.

Through our research for the book 'Disability Politics' (Campbell & Oliver, 1996) we identified the late 1960s as a watershed for disabled people's political mobilisation. Why the 1960s? We discovered through our research that it was too simplistic to suggest our liberation was 'learnt' from other civil rights movements that had been growing in number and power during the early 20th century e.g. gender, race or the US Vets challenges. I suggest that our movement's emergence took a fairly unique turn as it developed slowly - through an organisational process, i.e. disabled people coming together to either form our own pressure groups or 'take over' those controlled by non-disabled paternalists. Simply by breaking away from those who spoke on our behalf and finding a space where we could beg the question, why are we excluded from society? and how can we break in?, was the key to unlock some of the fundamental principles of the Social Model of Disability that has been the unique hallmark of our struggle.

I go on to explain why the organisation the Union of the Physically Impaired Against Segregation (UPIAS) and its founders were so crucial for disabled people's personal and then collective liberation.

I then demonstrate that it has taken at least the last twenty years for the Disabled People's Movement to really 'take off', which by the early 1980s it had, not simply via the BCODP, although the majority of evidence taken for 'Disability Politics' suggests it was the vital component. There was however a great deal of activity around disability arts, independent living, and pure access campaigns (transport, inclusive education, etc.), that were not directed

by BCODP but part of a broader groundswell of people aware of the oppression with tools to fight it.

As Richard Wood clearly states in 'Disability Politics',

"The definition of issues and the identity of ourselves as people distinct in society, in a unique position in society, has got to be the key success. It is our movement, nobody but disabled people own it"

A political consciousness does not in itself constitute a social movement and I will further illustrate how the awareness was transformed and built upon to the extent that we feel confident to say the disability movement has emerged but still experiences growing pains.

W H A T I S H I S T O R Y ?

Those first stirrings of disability protest that came from organisations such as the British Deaf Association or the National League of the Blind, are in much need of our contemplation and analysis. It is our deep hidden roots which will teach us more about our present struggles. However time is of the essence and alas this is not a historical thesis and our book was not a history of the movement. But it was a search into our past. A search for answers to questions that disabled people are raising more and more. Issues such as; Is there a Disability Movement? If so, what is the Disability Movement? How does it influence the shape or direction of our society? Who were/are, the movers and shakers? Does it really matter anyway?

I remember being appalled by my first History A level essay question:

History is more or less bunk. It's tradition. We don't want tradition. We want to live in the present and the only history that is worth a tinker's damn is the history we make today.

Henry Ford
The Tribune 25th May 1916
Discuss

If 'Disability Politics' taught me anything it was that 90% of my own personal liberation and the work that flowed hence came directly from learning from others who have gone before. Grappling with their ideas; turning them around

and about; using the tools to develop projects in disability equality training and infrastructures for independent living, has driven my entire working life.

Paddy Ladd, our contributor from the highly politicised deaf community admirably challenges Ford's famous quotation, when asked to consider our project:

“the process of freeing ourselves from imposed histories is in itself a historical and dialectical process. In these new and exciting times, whatever you or I set down are merely the first steps on the road to a full and comprehensive history of not just the disability movement as a whole, but of all its constituent parts of each particular disability group.”

This echoes the words of E A Freeman, that

"History is past politics, and politics is present history."

1865

We need to draw on the past, constantly revisiting as we develop our thinking. The process of researching and talking to contributors, for me has been of as much value as the final writing and publishing. And I just want to spend a short time talking about that process and the value of disabled people's _ historical accounts.

WHAT WE DID

As with so many civil rights struggles, time, energy and effort of those involved has been in action not words. Therefore most of what we wanted was probably inside the heads of those that were involved, not in published accounts.

Hence we decided to informally interview a range of disabled people (31 in all). Not a random sample but people we identified as having shaped, in some form or another, the transformation of our understanding of disability. There are many who might well have had a higher profile, who may wonder why their contribution goes unnamed. The truth is, we had to start somewhere with the resources to hand, so we could not include everyone who has made a contribution. For us it is simply the first look at when our Movement emerged into something quite tangible. When it began crossing boundaries and filtering into parts of life, that for centuries, had denied us in every way. Hence this chapter will concentrate on the Movement from a time when impairment boundaries were crossed and a united approach to social oppression took off.

THE EMERGENCE OF THE MOVEMENT

In the late 1960s disabled people began to question as a collective, the modus operandi of a plethora of predominately impairment charities. The charities, along with the quasi medical and social service professions who also dictated the direction and pattern of our lives began to come in for more overt criticism. Why the 1960s? We discovered through our research that it was too simplistic to suggest our liberation was 'learnt' from other civil rights movements e.g. gender, race or the US Vets challenges, although they were influential to the few that had access to the ideas. John Evans and Richard Wood, felt we "had our own version", rooted in our own historical and material condition. Crafted by the combination of individual vision and rejection of old forms of organisational representation and social exclusion.

I think what actually happened in the 60s - was an awareness that the issues were far broader, the single issues that that these single impairment groups had focused on weren't enough to satisfy the needs and aspirations of a wider range of disabled people

Richard Wood

By a wider range interest group, Richard meant that we were looking beyond our impairment and those who organised around it i.e. SCOPE, Royal National Institute for the Deaf/Royal National Institute for the Blind (RNIB), at the same time as looking beyond one barrier as the root of our exclusion. i.e. employment and physical access. This change was heralded by organisations like the National League of the Blind and Disabled and the Disablement Income Group. Although they of course helped teach us methods of political lobbying.

Simply by breaking away from those who spoke on our behalf and finding a space where we could beg the question, why are we excluded from society? and how can we break in?, was the key to unlock some of the fundamental principles of the Social Model of Disability that we hold so precious now. In Disability Politics contributors identified disabled people in the Union of the Physically Impaired Against Segregation (UPIAS) as the founders of this philosophy that relocated the burden of disability from the individual's problem to the way society was structured. The litmus paper for this shift was a short, yet profoundly powerful letter to *The Guardian* by Paul Hunt, in 1972, encouraging disabled people to join forces and vocalise their dissatisfaction with their lot in life, particularly if they were institutionalised.

Wednesday September 20th 1972

Sir,

Severely physically handicapped people find themselves in isolated unsuitable institutions where their views are ignored and they are subject to authoritarian and often cruel regimes.

I am proposing the formation of a consumer group to put forward nationally the views of actual and potential residents of these successors to the Workhouse.

Yours faithfully,
Paul Hunt."

Many respondents to Paul's letter went on to become involved in UPIAS either through meeting or corresponding through the internal circular. These years of debate were vital for the development of our collective consciousness and 'the institution' was a good model to explain our social position and disempowerment....

"I wrote to some of those who responded to Paul's letter. I started to visit institutions to talk about what people felt about being in an institution. This is where I began to make the connections..."

Anne Rae

"Paul lived in a Cheshire Home at that time. He introduced me to the real criticisms about the institutional approach. It seemed to me that the clearest perception of what was wrong with disability was in relation to these homes."

Vic Finkelstein

Our research threw up Paul's name and work time and time again. It is clear that he was able to see the way ahead with the greatest clarity and his ability to pass that on, enthusing others to act was pivotal to the emergence of the disability movement.

"Paul knew that the future lay in raising the awareness and political aspirations of disabled people in the community. UPIAS was Hunt's tradition. It was the tradition of the residents. We regard that as our inheritance. It was perhaps the greatest gift that we could have been given."

Phillip Mason

Such a personal and then collective release inevitably sparked anger followed by political demands. UPIAS prepared the way for the future national umbrella that would attempt to unite many different interest groups, under a common goal for full inclusion and the right to self-representation.

Later the British Council of Organisations of Disabled People organised around the UPIAS Principles, 1975:

DISABILITY IS A SITUATION, CAUSED BY SOCIAL CONDITIONS, WHICH REQUIRES FOR ITS ELIMINATION THE FOLLOWING:

That no one aspect such as incomes, mobility or institutions is treated in isolation.

That disabled people should, with the advice and help of others, assume control over their own lives.

That professionals, experts and others who seek to help must be committed to promoting such control by disabled people.

CONFLICTS EMERGE

It is interesting to note that we have not deviated from this approach, although the temptation to go down a narrower incomes approach, led by the Disability Alliance and the Disablement Income Group, was powerful. Disabled people at that time were still only too willing to leave political lobbying to the able-bodied experts, within these organisations and the piecemeal legislative entitlements that were secured via the Chronically Sick and Disabled Persons' Act and the various disability and attendance allowances helped maintain that status quo. Such 'benefits' were short lived and they naturally did not meet the growing aspirations and by the mid 1980s, frustrations, of an increasing mass movement. Maggie Davis recalls:

"DIG'S lack of success in establishing a national disability income was due to it, broadly speaking, falling into the hands of the experts - many of whom were able-bodied who were good at arguing and lobbying Parliament, and because it had become remote from the grass roots membership. Membership was little more than fund-raising fodder for this elite group of well versed Parliamentary lobbyists."

Our mobilisation took a fairly unique turn as it developed slowly through an organisational process, i.e. disabled people coming together to either form our own pressure groups or 'take over' those controlled by non-disabled paternalists. Such organisations were shaped to provide practical and emotional support but most importantly to challenge the entire British charity industry that maintained our oppressed state. 'Revolution' not 'Reform', was probably our biggest strength and remains so today. For those who believed that working within established organisations FOR disabled people, to change them, were doomed to be disappointed if not abused. Peter Wade, Paul's friend and colleague, took a reformist approach and joined the Royal Association for Disability And Rehabilitation (RADAR) and the Cheshire Foundation. The years that followed according to Judith Hunt, "were very unhappy ones as he battled to bring UPIAS principles to them and met a brick wall of hostility".

Hence BCODP's tradition of organising separately and then coming to the integrated table from a position of strength has been its hallmark. It has also been the cause of many internal and external disputes. Ever since the inaugural meeting in 1981 there have been heated debates as to what some 'perceive as our radical if not rigid discipline. Some say it is a legacy from the strict internal discipline of UPIAS, which put activists like Micheline Mason off for a decade.

I was emotionally and intellectually battered by some UPIAS members, so some of us went off and set up the Liberation network...a woman led organisation, embodying female values. It was open to all individuals and concentrated on peer support which we conducted through meetings and a magazine 'In From The Cold'. Here we really tackled the issue of internalised oppression, recognised by all marginalised groups as the major 'tool' of the oppressive society.

The Liberation Network's agenda was both impressive and extensive for its time:

We challenged the conditioned hatred of ourselves and each other as disabled people; we challenged the desire to assimilate; we challenged the denial of 'hidden' disabilities; we challenged the fierce competition between us, we challenged the inability to champion, appreciate and support each other's achievements or thinking (especially when it challenged our own); we challenged

the lack of information and understanding about issues of other oppressed people.

Perhaps it was too ambitious and too loose a coalition to survive the onslaught of debate and internal divisions that had to take place as we matured as a movement. Micheline also feels it was "prey to sexism" that undermined its theoretical and organisational basis. It folded, but only after "allowing a thousand flowers to bloom" for unlike UPIAS and early BCODP it provided a less rigorous, perhaps intensive forum for debate. Many active members went on to form organisations that have become vital parts of the movement - The Integration Alliance, Disability Arts and Culture, Disability Equality Training and so on.

THE EMERGENCE OF BCODP

Out of conflict comes harmony? Well not quite. Once it was agreed that the movement needed a national representative voice, we had to deal with who was in or out; our fundamental aims and objectives needed to be agreed and possibly the trickiest - the process of how we should get there.

Our interviews revealed many painful and hilarious anecdotes of conflict resolution as the movement's organisational base took shape.

I remember the first meeting. There were those people who were for and those who were against including certain groups. RADAR of course was raised as being so powerful they had to be in. But there were too many with a strong principled approach to let that happen at times that could be our downfall because we would not take a politically pragmatic approach - very naive.

Stephen Bradshaw

Eventually a fairly strict criteria for membership won through. No individual members, only organisations 51% controlled by disabled people. We started with 9 in a day centre in Camden - 15 years on we have 112 and have moved to a constitutional shift of taking individual membership. Our numbers if we tot up our member organisation's membership could well be in the 400,000s.

The member organisations provided the democratic bedrock of the British Council of Disabled People that became the focus of this national struggle to speak for ourselves and claim rights not charity. But does it signify an emerging movement?

Judith Hunt drew this conclusion.

Looking at the BCODP as the major focus, I certainly feel that it's been the point at which the movement became very visible and took on board the social interpretation of disability. But it was also the outcome of what had gone before. In a sense it was the build-up that began to take place in the 60s that was crucial.

We suggested in 'Disability Politics', that the disability movement and the BCODP are not the same thing. Rather, it became the formal organisational focus for a range of issues including critiques of state-based and voluntary sector-based welfare, the development of independent living campaigns and projects, struggles for ADL in all its forms, peer support, challenges to negative imagery and the stereotypes which perpetuate our exclusion.

WHAT KIND OF SOCIAL MOVEMENT IS IT?

Observers of social movements suggest that the transition from emerging to emergent movement is signified when the movement becomes larger, less spontaneous, better organised, and led by formal structures rather than *ad hoc* committees and informal groups. We would suggest the BCODP only signified such an 'emergence' from the late 1980s when more formalised activities around disability arts, independent living, and pure access campaigns (transport, inclusive education, etc.), that were not necessarily directed by BCODP but part of its outer margins, took place. In this process of drawing in a broader groundswell of disabled people and participating in a mutual education exercise i.e. BCODP teaching fundamental principles yet learning wider issues of oppression and how it relates to disability, we are gaining a powerful identity. As Richard Wood clearly states:

"The definition of issues and the identity of ourselves as people distinct in society, in a unique position in society, has got to be the key success. It is our movement, nobody but disabled people own it."

A political consciousness does not in itself constitute a social movement and an awareness of the cultures and dreams of its constituency and creating activities as a result, are what the BCODP constantly needs to engage in. This has not been an easy road to travel. Disabled people not only have to face oppression linked to impairment but many have to struggle against other forms of oppression, racism, sexism, heterosexism are probably the most obvious.

Nasa Begum expresses the dilemma that people face who experience as she calls it 'simulations oppression' within the movement:

Many of us will identify with different bits of our identity at different times. It all has to be addressed when it presents itself. Sometimes the appalling treatment I have experienced in hospital has come from being disabled; but some is around being black and there's this sexism crap they come out with because I'm a woman.

Lots of black disabled people identify disability as the main issue, they are encouraged to do so by their white peers who dominate the movement. We shouldn't be trying to separate identity. But the reality is that some of us at different stages of our lives, are going to identify with different things as at that particular point it will be more pressing perhaps. The movement must show more tolerance.

The greatest and perhaps hardest challenge to be faced are the alliances that need to be made with other oppressed groups, other civil rights activists and impairment groups within our movement who do not feel a part of the common struggle. The criticism and conflict that comes with this issue, coupled with the lack of financial and human resources to tackle it, has often led activists to immobilisation rather than activity.

However, there have been some successes. One of the largest impairment groups - people with learning difficulties, have been historically excluded from the movement's activities. In Disability Politics Simone Aspis, representative from People First National candidly wrote We face discrimination in the disability movement. People without learning difficulties use the medical model to describe our needs. We are always being asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as people with physical impairments. We want to concentrate on our access needs in the mainstream disability movement.

People without learning difficulties in the movement still fear being lumped together with us. Being put together with what society see the 'stupid, thick, mental and mad', would reinforce the stereotype that disabled people are incapable.

Equality will come within the movement when people with learning difficulties are given positions of power and influence within the movement like chairperson or spokesperson.

1994 was the year that this issue was raised vehemently, in all areas of BCODP; it has been tough, some allegations were hard to hear, but as a result

of nettle grasping, things have moved on. For example People First joined forces in representing throughout the passage of the Direct Payments Act.

CONCLUSION

I have concentrated on some of the organisational and political issues that have confronted those who have sought to provide a representative base for disabled people's social influence. I have been highly selective, picking out bits and pieces of the jigsaw to give a taste of our rich recent history, which explains so much of where we are today. A continued investigation and validation of our past so that disabled people new to the movement will feel clearer as to the movement's intentions for a better society, was the clearest message that came out of the research for the book. For one of the factors I came to understand was that we are a new social movement and what makes us different from other kinds of political organisation, is that as well as building an organisation and achieving political gains, we have to continue to seek to transform the consciousness of the membership.

It will be the development of the social model as the link between concrete _ achievements and developing consciousness, that will take us forward:

Richard Wood illustrates this well;

There was the intensity of uncertainty of people still unsure about just how and if we were going to be able to take on board the broad range of issues that faced us. I think the thing that started to make it clearer was the total acceptance of the social model as being the core of the movement, which it soon became. It was something people could adopt and feel part of and most importantly use as a tool.

The development of the social model and its journey into the very fabric of our communities through social, political and economic infrastructures, gives the disability movement the authority to say we have emerged. Whilst we are still experiencing 'Growing Pains!' we are making a unique contribution to the world's future.

REFERENCE

CAMPBELL, J AND OLIVER, M. (1996) 'Disability Politics: Understanding Our Past, Changing Our Future', London: Routledge.