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**USER INVOLVEMENT IN THIS VOLUNTARY SECTOR
- A VIEW FROM THE DISABILITY MOVEMENT**

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Introduction

It is somewhat ironic that at this point in our history, while the voluntary sector is larger and more powerful than it ever has been, it is also subject to critical attacks and is under considerable pressure to reform itself or be reformed. This paper will discuss this by focusing on disability organisations, their recent experiences and the challenge they present not just to the future of disability organisations but to the voluntary sector more generally and indeed, society itself.

The rationale for focusing on disability organisations and the issues that confront them are the following;

- (a) there is a large and powerful voluntary sector working in the field of disability whose historical roots go back to nineteenth century Victorian paternalism
- (b) in recent years a fundamental split has emerged between those traditional organisations for the disabled and the newer more democratic organisations controlled and run by disabled people themselves
- (c) both kinds of organisations have been centrally involved in policy developments in recent years, prompted by Governmental concern with issues of 'user involvement'
- (d) within disability organisations, there is an ongoing struggle over the issue of 'voice'; that is, who should speak for disabled people.

These factors mean that a case study of the issues facing these organisations are of central relevance to the voluntary sector more generally. While the debate about voice may be more advanced in disability organisations, it permeates the whole sector including organisations concerned with elderly people and those with AIDS, for example. Hence, because disability organisations are in the vanguard of these struggles, we can draw inferences about the future of the whole sector from what is happening therein.

It must be emphasised at the outset that this paper is a personal view and not an agreed paper from the disability movement as a whole. However, it is based upon recently completed research on the emergence and significance of the disability movement which will be published shortly (Campbell and Oliver 1996). See Appendix A for further details of how the study was carried out.

Additionally, I have been active in the movement for the last twenty years and as such, it represents my impressions of the view of the movement in respect of the voluntary sector generally and its relationship to other organisations involved in the disability field. To put the matter succinctly, this paper is what I think the disability movement thinks, not what it has collectively agreed.

It should also be made clear at the outset that the afore mentioned study was unashamedly an insider account of the rise of the disability movement. As well as being an insider account, it was also a partisan one in the sense it was not an attempt to be 'objective', whatever that may mean, but one which was based emerging disability movement social movement and not as a upon the premise that the newly could only be understood as a new development in voluntary organisation and activity. This is the position that will inform this paper as well.

Defining disability and the disability movement

In an earlier publication (Oliver 1990.117-8) I provided a scheme for classifying the various kinds of voluntary organisations working in the disability field.

Typology of disability organisations

- (1) Partnership/patronage
- (2) Economic/parliamentarian
- (3) Consumerist/self help
- (4) Populist/activist
- (5) Umbrella/co-ordinating

This was meant to be illustrative of the complexity of organisational activities and forms that exist. However while many of the distinctions made have subsequently blurred or proved to be insignificant, a crucial distinction between the various organisations remains; whether they are controlled and

run by disabled people themselves or by what one commentator has called 'highly paid accountants and managerialists' (Brandon 1995).

This distinction began to emerge in the 1960s with the coming of the 'age of affluence' when disabled people began to organise around issues of income, employment, rights and community living rather than institutional care. It was given further impetus in the 1970s with the failure of the Chronically Sick and Disabled Persons Act (1970) to provide a welfare solution to the problems disabled people were facing and the formation of the Union of the Physically Impaired Against Segregation (UPIAS). It continued into the 1980s with the emergence of national and international co-ordinating bodies and has been a crucial element in the emergence of demands for user involvement and empowerment in the 1990s.

The result of this has been a transformation in our understandings of disability. At the heart of this transformation has been the rise in the number of organisations controlled and run by disabled people themselves. At the beginning of the decade of the 1980s there were very few such organisations but by 1990 there was an international organisation known as Disabled Peoples International (DPI) and a national co-ordinating body, the British Council of Organisations of Disabled People (BCODP). By this time the BCODP's constituent organisations had risen to over a hundred, most of whom are local coalitions of disabled people or centres for integrated living (CIL's).

By any standards this numerical growth is remarkable but there are four reasons why it was even more remarkable than appears at first sight. Firstly, all organisations controlled by disabled people suffered from chronic underfunding throughout the decade, even from national and international agencies which are supposed to support such developments. Secondly, many politicians, policy makers and professionals had no faith in the viability of a new movement which was being built by people who had so far seemed passive and dependent. Thirdly, the new movement was built in the teeth of opposition from the traditional voluntary organisations who, up to then, had been in control of disability and this opposition was often active rather than passive. Finally, because of the disabling environments that disabled people encounter, the difficulties involved in simply finding ways to meet, communicate and organise, should not be under-estimated.

This remarkable growth was not merely a numerical phenomenon, but also reflected the individual and collective empowerment of disabled people through the organisations they were creating. This can be seen in a number of ways. It can be seen in the challenge to dominant social perceptions of disability as personal tragedy and the affirmation of positive images of disability through the development of a politics of personal identity. It can also be seen in the development and articulation of the social model of disability, which by focusing on disabling environments rather than individual impairments, offered an alternative conceptualisation of the problems that disabled people faced.

Consequently, the direction of disabled people's personal energies turned outward to building a force for changing society.

The social model of disability has been fundamental in carrying the movement forward at such a remarkably rapid pace. Finally, it can be seen in the numbers of disabled people 'literally' taking to the streets, not only as a form of social protest but in pursuit of their everyday lives.

Why does this constitute, a social movement?

The decade of the 1980s has seen a range of new social movements develop from environmentalism and the green movement, through the challenges to social oppression by groups such as women, black people and gays and lesbians, and onto a resurgence of the peace movement. These new movements differed radically from older movements which had tended to campaign on single issues, were led by experts and saw parliamentary lobbying as their only tactic.

The new movements were much more concerned with a broad range of issues, were populist and used a variety of tactics. It should be pointed out however, that there is much academic debate and dispute over the nature and significance of these new movements. The position taken in this paper suggests that these new movements, both individually and collectively, will pose significant challenges both to traditional voluntary organisations and existing political institutions in the foreseeable future.

Providing a precise definition of the disability movement is, therefore, no easy task but Barbara Lisicki, a prominent member of the Direct Action Network (DAN), comes nearest to an acceptable definition.

"I don't think anyone knows for sure what a movement is but essentially what we are talking about is a set of ideas and an analysis which people can then support in different ways. I always think of the movement as a set of people that have somehow made a connection with a set of ideas. The disability movement is obviously a set of ideas that presents a challenge to dominant ideology that says disabled people are burdens on society and that they should be taken care of but the disability movement is also about people who believe that they have right to a life".

The Challenge to Traditional Disability Organisations

The emergence of a strong and vibrant disability movement, however defined, has raised important questions about the existence of the traditional organisations, their views on what the problems of disability actually are and their own role in the world.

The first challenge posed by the emergence of the disability movement concerns the issue of 'voice' - who do the traditional organisations speak for? Until recently it was usually assumed that the organisations spoke for those groups who were named in their titles and that they were entitled to do so. This assumption was often made by government, local authorities and even the general public. Certainly the senior staff of the organisations concerned assumed they were entitled to speak for their named constituency and many still do to the point where they are quite happy to advise government on a whole range of issues.

However, with the coming into existence of the disability movement such claims can no longer be taken for granted. Several of the larger of the traditional organisations have had to face challenges in this respect; notably SCOPE (formerly the Spastics Society), MENCAP and the Muscular Dystrophy Association. Others like the Royal National Institute for the Blind (RNIB) have sought to respond to this challenge by including more blind people in their governing structures.

The crucial question that this raises is whether and how far traditional organisations can go in changing their structures in order to become the legitimate voice of the communities they purport to serve. So far, with the notable exception of the Greater London Association of Disabled People (GLAD), very few of these organisations have managed to democratise themselves to the point where they can legitimately claim to be representative organisations. The question of the claims of the disability movement itself to be representative will be returned to in the next section.

The second challenge is that of innovation - where are the new ideas about disability coming from? One of the rationales for the voluntary sector has been that it is, often the vehicle through which new ideas emerge and are developed in practice. However, as has already been described, the 'big ideas' about disability - independent living, civil rights, the social model,

direct payments, positive disability imagery - have all emerged from the movement itself and not from the traditional voluntary sector.

Indeed, it could be argued that the organisations for the disabled often stood in initial opposition to many of these ideas, later became reluctant converts before attempting to take them over with almost evangelical fervour. The campaign for civil rights legislation is a good example of the way this transition has worked within many of these organisations who initially opposed the idea of civil rights legislation, became reluctant converts and who now promote the issue as if they invented it all by themselves.

This raises the question about whether it is the ownership of these ideas which is important in itself or the way these ideas are promoted. In practice however, these things cannot be separated for organisations which merely take on the ideas of others often do so in distorted or counter-productive fashion. SCOPE's recent campaign to promote positive imagery through public advertising is perhaps a good example of this taking on an idea of others but failing to develop it in any meaningful or productive way.

If economic criteria are used to judge its effect, the funds raised by SCOPE dropped considerably during the campaign. Contrast this with the success of the disability movement in promoting its own ideas of positive imagery in the success of the campaign to force the independent television companies to abandon telethons.

The third challenge concerns accountability - to whom are these organisations accountable? The crucial distinction between organisations for the disabled and those of disabled people is that the latter are controlled by disabled people themselves. In order to be eligible to join the British Council of Disabled People (BCODP), disability organisations are required to provide constitutions which ensure that at least 51% of the governing body is made up by disabled people and BCODP itself meets this requirement in order to be a member of the world body Disabled Peoples International (DPI).

Obviously all voluntary organisations are required to provide rules concerning the governance of their organisations but few of the organisations for the disabled have specific requirements or quotas in respect of disabled people. This means that these organisations have the capacity to act without reference to the wishes of disabled people themselves and often,

because these governing councils have little direct experience of disability, the professional staff have great autonomy and are able to act with little or no reference to their structures of governance.

The recent decision of the chief executives of six of the larger of these organisations to issue a press release pledging themselves to work with the Government on the Disability Discrimination Act (1995) despite their commitment to Rights Now, a confederation of organisations in which they were active members, not to support this legislation, raises fundamental questions of accountability within these organisations.

The final challenge is one about control - who actually is in control? While all disability organisations have to develop relationships between state and government at local and national levels, the connections between organisations for the disabled and state institutions is much greater in at least two respects; firstly they receive much greater amounts of funding both as direct grants and more recently as service level agreements, and secondly there is much overlap between membership of these organisations and other state institutions cemented by the honours system and other forms of patronage.

While it would be overstating the case to suggest that these factors mean that these organisations for the disabled are nothing more than state institutions by another name, their capacities to act independently of and possibly in opposition to government are open to question.

Who does the disability movement represent?

Critics, including organisations for the disabled, often focus on the representative nature of the disability movement itself and accuse it of not speaking for all disabled people. This is certainly true but then no representative organisations represent all of their constituency. Vie Finkelstein, a founder and first Chair of BCODP, is forthright about this.

"We shouldn't deny that it is a minority of disabled people who belong to the BCODP. If you say there are 7 million disabled people in Britain, obviously only a tiny minority are politically active in disability movement. We shouldn't deny that. The BCODP reflects a tiny minority, but the Thatcher government was elected on a minority of the

electorate".

Richard Wood, current Director of BCODP, is adamant that the key factor that separates the BCODP from other disability organizations is that it was built by disabled people, it exists because of disabled people and if we withdrew support from it, it would cease to exist.

"It's unquestionably true that it's what we've created. That's the unique thing about it. Nobody has elevated the BCODP to this position of - in the same way as, say, DIAL UK has elevated itself into a position of first creating the organisation and then saying it's the national one. The BCODP has not self elevated itself. It is where it is because disabled people ask it to be there. If disabled people didn't want it to be there they could dismantle it again".

There is another issue that needs to be considered; the role of the disability movement (and indeed the organisations for the disabled) in wider aspects of British politics. Britain is what might be called a representative democracy in which a variety of groups, interests and parties are accorded the legitimacy to speak on behalf of whole constituencies or groups of interest. But representation in representative democracy is always considerably less than perfect, as Vic Finkelstein points out.

"My position was that in a representative democracy where people organise and present their views you take those views to represent the group they say they're representing until other organisations emerge to challenge them. That's what democracy is about. In as much as there is no other reflection of their views these are the views. The fact that it's a minority membership is true but the question then is 'who speaks for the majority?'. I once gave a talk to a medical disability group and they raised this issue. They said 'these views you're putting forward are interesting but they only represent a minority of disabled people,. So I said, 'who represents the majority?' 'You?' Of course, they just became embarrassed because if it isn't us it's them, the doctors".

Or, one might add, the traditional organisations for the disabled.

In representative democracies, representation is always less than perfect. For example, the Conservative Party does not represent all conservative voters nor does the British Medical Association represent all doctors. No-one would dream of denying the claims of the Conservative Party to represent conservatives nor the BMA to represent the views of doctors. And yet the right of the disability movement to represent disabled people is continually questioned, by politicians, policy makers and professionals alike.

This point is developed by Altman (1989) in making a distinction between what he calls 'movement' and 'community'. He develops this further in the context of gay politics.

"We can think of the gay world as consisting of a number of concentric circles: at the centre are those people who openly identify as gays, and whose social and communal activities exist largely within a gay milieu. Then there are those who are openly gay, but not in all areas of their work and social life. Then there are those who accept themselves as homosexual but do not feel part of a larger gay community as a result. Lastly there are very many people who are behaviourally homosexual but do not consider this as part their identity. The gay movement will draw almost exclusively from the first two categories, but these are themselves in part the product of the movement. Both identity, and conscious affiliation to the gay community, are processes which change over time in an individual's life".

(Altman 1989.47-8)

This distinction between movement and community is a useful one in considering the politics of disability. Certainly it would be true to say that not all of the six million disabled people in Britain see themselves as part of a disability community, let alone as supporters of the aims or the tactics of the movement.

What is true however is that issues that the movement has placed on the political agenda such as rights, access, choice and control are issues relevant to the wider community of disabled people.

What is also true is that increasing numbers of disabled people within that community are identifying with and joining movement. And what is undeniable is that if the legitimate claims of the movement to represent the interests of disabled people are denied, who else will represent these interest;- doctors? politicians? the Royal Institutes and Associations of the traditional voluntary sector?

An evaluation of the disability movement itself

According to Marx and McAdam (1994), there are four criteria against which any social movement (new or not), must be judged. These are whether any new political or economic changes have resulted from their activities, whether any specific legislation has resulted, what changes in public opinion and behaviour have been produced and whether any new organisations or institutions have been created. These criteria will now be used to evaluate the impact of the disability movement so far.

(1) new political or economic changes

It is difficult to provide hard evidence that at present, the activities of disabled people in Britain have produced substantial improvements in their lives. The work of Barnes (1991), using data from a wide range of official sources, demonstrates that the majority of disabled people in Britain lead lives that are significantly worse than their non-disabled counterparts.

In international terms, the situation is even bleaker. A recent UN report (Despouy 1993) confirmed earlier estimates that there are more than 500 million impaired persons in the World; that is one in ten of the World's population. The report goes on to suggest that

"... these persons frequently live in deplorable conditions, owing to the presence of physical and social barriers which prevent their integration and full participation in the community. As a result, millions of disabled people throughout the world are segregated and deprived of virtually all their rights, and lead a wretched, marginal life".

(Despouy 1993.1)

Clearly then much needs to be done to improve the material conditions under which disabled people live throughout the world. It would be wrong to conclude from this, however, that the disability movement has failed to achieve any economic or political changes. To begin with, the movement is very young and is still struggling against the old, traditional approaches based upon the individualisation and medicalisation of disability. Additionally the movement has succeeded in giving a voice to disabled people and making sure that this voice is heard at the relevant political and economic fora in Britain as well as throughout the world. The crucial issue for the movement over the next few years is to make sure this collective voice is not merely heard but taken notice of.

(2) specific legislation

In terms of the legislative impact of the movement, there are two issues that need to be considered. Firstly there is the impact that the movement has had upon the existing legislative programme of government. Over the years, the movement has been able to make a contribution in this area without becoming solely a parliamentary lobby group or becoming too closely identified with the political process. Rachel Hurst, a past Chair of BCODP and currently Director of Disability Awareness In Action, sums up the movement's contribution thus.

"The input that we did have was important to the legislation at that time. The fact that we were, by that time, part of all that was important. Equally the fact that more and more disabled people were able to hear what it is that it's all about was important".

The major impact that the movement in Britain has had has been in terms of the promotion of the idea of what was initially anti-discrimination but what has now become civil rights legislation. While not yet on the statute books, the movement has succeeded in converting all of the political parties and the vast majority of voluntary organisations to the idea of legislation to outlaw discrimination and indeed, even a recalcitrant Conservative Government has passed its own, piecemeal legislation. This is no small achievement when put in the context that only fifteen years ago some of the organisations for the disabled were agnostic to the issue, and the vast majority were antagonistic.

There is a final area where the movement has succeeded in producing new legislation and that is in the promotion of independent living by making it legal to pay disabled people cash to purchase their own personal assistance services. Richard Wood describes the way the movement brought this about.

"one of the best things that the BCODP did was to set up the Independent Living Group and have people who do use PA services, and hence understand what all that means, not only direct the research, but provide the solutions and point to the way forward. I see the BCODP as a facilitator of that, as a vehicle that will allow people to come together, create the environment where they will come together, and project the arguments that they asked us to project"

Direct payments to disabled people, which have been illegal since the National Assistance Act of 1948, will be legalised in 1996 and that is solely attributable to the disability movement.

(3) changes in public opinion and behaviour

Judging the extent of changes in public attitudes and behaviour is a very difficult task, particularly in an area like disability where there is very little research evidence on which to make a judgement. John Evans, another former Chair of BCODP, points out that disability is often a neglected issue.

"It would be nice to see disability raised up the agenda a little bit more. But it's not going to be that easy because, while in the case of environmentalism everybody can identify with it, it is not the case that everybody identifies with disability. Even though there is the idea that it can happen to anybody and to a certain extent it does effect everybody but people don't necessarily relate to it in that way. It's trying to develop those things a bit more so that they become higher up the public agenda".

This comment was made before the civil rights campaigns that have taken place in 1994 and 1995 and the proliferation of peaceful civil rights demonstrations orchestrated by the Direct Action Network. These have clearly had a major impact on public opinion at least, and aside from a minor

right wing backlash, there is overwhelming support for disabled people to be given the full entitlements of citizenship. From editorial support in the tabloid newspapers to the support of the inconvenienced public at demonstrations, it is clear that public opinion now recognises the discrimination disabled people face and supports the campaign of the disability movement to eradicate it.

(4) the creation of new organizations and institutions

One of the central issues in any evaluation of the disability movement is whether organisations such as the BCODP constitute new organisational forms. Stephen Bradshaw, a founder member of BCODP and long-time Director of the Spinal Injuries Association, while endorsing the principle that disabled people must do it for themselves, does not see the creation of new organisations as the only way ahead.

"I'm a great believer in peaceful revolution and the idea that there's no way to salvation except through toil. But the idea that you can only get to god my way; that you can only get to Nirvana through the BCODP - that's impossible. Not that I'm a religious person".

He goes on to suggest that the conversion of the old, traditional organisations for disabled people into democratic and accountable ones is also a realistic possibility.

"It's been done with GLAD and for different reasons RNIB is actually fairly close. RADAR is getting closer all the time".

Richard Wood does not agree and reaffirms the principles of accountability and democracy.

"The BCODP is a grass roots organisation. We must always hold onto that. The BCODP is not the tail that wags the dog. The dog is its member organisations; that is what we are at the end of the day. We're an important tail, but we only exist because our member organisations exist and will us to exist to carry out a role that they've defined for us. The thing to realise is that in terms of our ability as disabled people to tackle the issues, present the

solutions, we have to refer back to the grass roots. We have to refer back to the people who are living with discrimination day to day".

He goes on to suggest that, unlike the traditional organisations, the BCODP has always managed to remain independent of what he calls 'the establishment'.

"One of the things that we can be proud of in the BCODP is that actually we've never gone down that road of being part of the establishment".

Throughout this paper it has been argued that the disability movement is not just a social movement, it is a new social movement. Therefore it is necessary to refer to three other criteria which differentiate between narrow, politically focused social movements and the new more broadly based ones in order to evaluate these claims further.

(5) consciousness raising/education

In evaluating how far the disability movement has come in education and consciousness raising, we must remember the situations in which many, possibly even still a majority of, disabled people are placed. Patricia Rock, currently Chair of the British Council of Organisations of Disabled People Womens Group and Co-Chair of Disabled Peoples International European Disabled Womens Committee, graphically points this out.

"The majority of them are not given the opportunity to become politicised, they're stuffed away in day centres and institutions and they're individualised, and their services are individualised. My great hope is that we will allow disabled people to feel that there is someone that speaks for them; that they feel they can be party to. Our historical fate has been divide and rule;- services for the mentally ill, services for the mentally handicapped, and services for this and that. We've got to realise that we've got to throw the cake away; in fact there isn't a cake. We want to create something that's new. We've got to think collectively. Most disabled people don't think collectively".

Rachel Hurst makes a similar point, arguing that we are socialised in particular ways and we need to throw off the shackles of this socialisation collectively.

"So many of us fulfil our stereotyped destinies and we need to show that we shouldn't. We don't need to. If there wasn't this constant feeling of negativity about disability or negativity about impairment".

She focuses on the rejection of 'the cure' as part of the collective consciousness raising exercise.

"All of us are saying we don't want to be cured because actually we think we're better people as disabled people than we were when we weren't".

Despite the many difficulties involved, it is clear that an arts and cultural movement has established itself within the disability movement more generally. While the precise nature of its achievements may be difficult to estimate, it has raised the issue of 'disability pride' and made many disabled people feel that they do not have to be ashamed of or apologise for their impairments. This educative process has undoubtedly been an empowering one.

(6) internationalism

Another factor which distinguishes new movements from others is that they often have international dimensions and they raise important issues for the global community to deal with, not simply nation states. According to Richard Wood, a collective international movement has collective international responsibilities.

"The recognition, which is now becoming a global recognition, that economic situations vary, degrees of oppression vary profoundly, but basically we do all face the same forms of discrimination. I think that we have a responsibility in countries where we have democracy to present the issues for people in countries where they don't, and are unable to do so for a variety of reasons".

One way of achieving this is to move beyond the social model of disability, formulated in the context of particular kinds of societies, and to develop approaches relevant to disabled people all over the world.

"Now the movement is moving forward into saying 'This is not just a social model of disability, it's a human rights model of disability'. The next few years are going to be about defining what that model is and what implications it has for our own national movements and the international movement. The BCODP has a major role to play in Europe, and the DPI has a major role to play in the World: in tackling the UN Commission on Human Rights and through the EEC".

(7) human rights, civil rights and citizenship

This leads to the final criteria against which new social movements should be evaluated; the extent to which they can secure human and civil rights for their membership. Richard Wood points out the need to build up alliances with other organisations campaigning around rights issues.

"I'm very excited about links that the BCODP is now making with people like Liberty. I'm also very excited that at last we may have the chance to educate them, because I think that in terms of disability issues they need some serious education. But at least that forum is starting to open up and the BCODP will be playing a key role in that. It augurs well for the future, it also augurs well for our ability to maintain our position as a radical but constructive voice of disabled people, a voice that can now work alongside other civil rights groups. It will enable us to retain the vision. The old saying 'if you haven't got a mission, you're not going anywhere'. I think having that vision of equality for all citizens is our mission".

He goes on to link this to the internationalism of the movement and the spin-offs that this produces at the national level.

"The setting up of the DPI Human Rights Task Force is a very, very significant step, because it moves disability issues into a new dimension. We're even starting to see that in this country. It is now commonplace to hear people talking about human rights when talking about disability. The two things just naturally go together now, and even talking to the Government we're talking about human rights - we're not talking about disability issues. I think that is really profound".

Empowering disabled people

One thing that the disability movement can claim to have attempted is that of empowering disabled people, although the very word has taken on so many different meanings in recent years. According to the new right, it's the new consumerism, giving people freedom of choice particularly in areas of life that had been taken over by the State like health and education. According to the new left, empowerment is the new welfarism involving consultation and partnership with service users of all kinds. According to professionals working within the welfare state, it is about managing the process of care.

Common to these differing approaches is the assumption that empowerment is a process by which those in society who have power can dispense some of this to those who don't have any. This underpins many recent social policy developments where it is assumed that politicians and policy makers can create an empowering environment and professionals through the development of appropriate practices can empower their clients. Central to this notion is a discourse which renames clients as 'users' or 'consumers'; which is supposedly empowering in itself. Not only that, but the process of empowerment somehow becomes objectified as a thing; what's more a thing that can be delivered by those who have it to those who don't.

A study which encapsulates this view was published recently and contains a section entitled 'Managing for Empowerment'. It further states the beliefs of its authors

"We have believed since our original study of social service teams in the 1970s that the person with most influence upon the service which the user receives is the

first line manager. He or she thus plays a vital role in user and carer empowerment" . (My underlining)

(Stevenson and Parsloe 1993.12)

James (1994.6) makes the same point

"Empowerment of users is not a bolted on extra to managing welfare, but central to it"

Means and Smith (1993), in their book on recent developments in community care policy, try to seriously assess the impact that the emerging disability movement has had on policy debates. Overall the authors are optimistic, welcoming the arrival (at last) of social service departments as the lead agency in the community care reforms. They suggest that these departments are taking the challenges of community care seriously and 'are open to learning how to succeed'.

Certainly as far as disabled people are concerned, there is little evidence in the way that social services have operated since their inception in 1970, to suggest that they deserve the lead agency role or that they have the skills and capacities to deliver enabling and empowering community services. Despite this and recent evidence (much of which they acknowledge), that all is not well with the community care reforms, they still suggest that

". . . the emphasis of the reforms upon user involvement and empowerment has legitimised the voice of the user, carer and disability movements in a way that was not the case previously.. " (p.223)

Given the lack of evidence to support this view, we suggest that part of the reason for their optimism is that their discussion of power is both outdated and oversimplified. A more realistic conception of power would recognise that both economic and social markets operate on the basis of power relations where politicians, policy makers and professionals still have power and service users don't. The rhetoric of rights to assessment and even rights to services have done little or nothing to change that.

Seeing power as a process of struggle at both the micro and macro levels would have enabled them to have been much more critical of what the

french philosopher Foucault might have called the discourse of community care. While they are critical of idealistic and utopian notions of community, they do not subject the idea of 'care' to the same critical scrutiny. And like all liberal academics before them, they fail to recognise the irresolvable contradiction between the ideas of empowerment and care. To put it bluntly, people in need of care cannot be empowered because the reason that they need care is precisely because they are powerless;- if they were not, why would they need care?

The British Council of Organisations of Disabled People (BCODP) pointed this out as long ago as 1986 in response to the original Audit Commission Report on community care which set the train of the new reforms in motion, arguing that the ideology of care is far more pernicious than the idea of community. As Richard Wood, Director of BCODP pointed out more recently

"For each and every disabled person the words 'choice' and 'control' are of paramount importance. These are the words, not care, which should underpin all policies and strategies which impinge on our lives"

(Wood 1991.202)

Government policy on empowerment

Beginning with a damning report on community care from the Audit Commission (1986), the Griffiths Report (DHSS 1988) followed some two years later and after much delay, this was incorporated into a white paper "Caring for People" (DHS 1990). After a very short consultation period the white paper was incorporated into the National Health Service Act (1990) which has been fully operational since April 1993.

Central to this is a new managerial strategy for providing services which is to be supplemented by a market strategy which involves stimulating the private and voluntary sectors to act as providers of services and for the statutory authorities to act as enablers and purchasers of services rather than sole providers. What this will mean in practice is that health and social services will no longer have to be sole providers. In fact, they will have a duty to purchase welfare services at the cheapest cost commensurate with maintaining appropriate quality.

By opting for this combination of market and managerial strategies, the Government hoped that the problems of professional dominance and dependency creation would be addressed. However, markets are characterised, at least in economic terms, by a balance of power between buyers and sellers. Unfortunately, such a balance does not exist in the social welfare market, given the history of the domination of welfare services by the professionals who provide those services and the inability of the traditional voluntary sector to adequately represent the needs of users.

This crucial issue has been addressed by adopting what might be called 'an empowerment strategy', which has involved the production of a range of charters specifying the rights that people can expect from public services. Additionally, the Government has produced a plethora of documentary advice on how to involve users collectively and individually in service planning, provision and delivery. One commentator has claimed "It's no longer a question of 'is user involvement a good thing?' Users' organisations demand it. Legislation requires it". (Beresford 1992).

While it is too early to be definitive about the ways in which the drive to user involvement is working, it has to be said that the early signs are not hopeful. There is little evidence that disabled people are being involved in the planning and delivery of services in the way that legislation requires (Bewley and Glendinning 1994) . Nor is there much evidence that local authority assessment procedures adequately reflect the legal requirement to place the needs of users at the centre of the reforms (Ellis 1993). Finally, studies that have recently been carried out are not optimistic that the existing reforms are enough and unless further changes are made, as far as disabled people are concerned, 'their opportunities to be independent citizens will disappear' (Morris 1993a.1993b).

In probably the largest recent study of the relationship between Government and the voluntary sector in Wales (Drake 1994), of the 129 agencies providing information three quarters were not controlled by disabled people using the criteria specified earlier. Despite this the study

" . . demonstrates a very high measure of statistical significance in inverse relationship between income and the proportion of disabled people on the governing body of an agency".

(Drake 1994.473)

In other words, despite Government rhetoric on user involvement, it is to those organisations for the disabled that the vast majority of state finance was allocated. Further analysis of the data led to the conclusion that

" . . . consumer involvement has been interpreted within the structure of traditional charities and has posed no threat to the dominance of non-disabled people".

(Drake 1996.000)

While no similar studies have been undertaken in the rest of Britain, few would disagree that the findings of any such study would be very different, indicating that Government policy of user involvement and empowerment is more rhetoric than reality: to put it bluntly, there is little evidence to suggest that the Government is prepared to put its money where its mouth is.

The real nature of empowerment

It has to be recognized that empowerment is a collective process on which the powerless embark as part of the struggle to resist the oppression of others, as part of their demands to be fully included into society, and to articulate their own definitions of themselves and their own views of the world. Central to this struggle is the recognition by the powerless that they are oppressed; first articulated in respect of disability by the Union of the Physically Impaired Against Segregation in the 1970s (UPIAS 1976).

Collective empowerment then becomes the process by which groups begin to struggle against this recognised oppression as the writings of people like Freire (1972) and Biko (1978) graphically demonstrate in respect of South America and South Africa and the early writing of Sutherland (1981) describes in respect of disability. At the heart of this process of empowerment has been the rise in the number of organisations controlled and run by disabled people themselves and already discussed in this paper.

The process of collective empowerment is not something that only disabled people are undergoing. In the late twentieth century, economic and technological changes, social disorganisation, changing patterns of family life and ecological crises, have led to feelings of disenfranchisement more generally. This is beginning to have an influence on the political system with

the emergence of many new groups of all kinds; environmentalists, pacifists, the unemployed, welfare recipients, minority groups and the like.

The rise of these broadly political movements (called new social movements in this paper) is occurring at precisely the same time as fundamental questions are being asked about the nature of democracy itself and whether it can be continue to be exercised solely through the political party and the ballot box. Indeed one could say that the current party system isn't a party system anymore because the same kind of policies operate in all parties and the opportunities for people to make meaningful choices no longer exist.

Other political institutions of the 20th century appear to be showing signs of disintegration, including the monarchy. With its obvious connections to the traditional voluntary sector, this again raises questions about the legitimacy and future of organisations who existence depend not on support from their membership but on patronage and charity. All this suggests, as far as disability organisations are concerned, that beginnings of the demise of the old and the beginnings of the rise of the new is not merely a coincidence. Profound changes may well be underway leading to political institutions and voluntary organisations in the twenty first century that are going to be radically different from those currently in existence.

Conclusions - what does it all mean?

Frances Hasler, director of GLAD suggests that the disability movement has done nothing less than change the meaning of disability for everyone.

"During the 1980s the disabled people's movement has changed the discourse on disability in Britain. It has done this both by enabling disabled people to be active in public life, and by redefining the meaning of disability"

(Hasler 1993.284)

Ken Davis, founder member of the Derbyshire Coalition of Disabled People, suggests that the movements very survival was a crucial achievement because

"With this, the tradition of grinning and bearing unjust laws came to an end. The redefinition of disability as a

form of social oppression had, in the last resort, validated the public expression of disabled people's deeply felt anger".

(Davis 1993.290)

The disability movement has indeed survived and has undoubtedly had a profound impact on the meaning of disability throughout society to the point where none of this is reversible. Disabled people as a collectivity will never again be the passive, dependent individuals that they have been for much of the twentieth century and this raises profound questions for the future and finally, I will attempt to pose and answer some of those questions.

Again, it should be emphasised here that the questions being posed and answered are ones that I think are significant, and indeed, that I think the disability movement thinks are significant. Organisations for the disabled might well come up with a different set of questions and almost certainly would come up with a different set of answers to the questions I am posing.

The first question concerns the future of the movement itself. In my view the movement will go from strength to strength because of the pent-up energy of disabled people, excluded and oppressed for centuries, that it can now draw on. This ongoing process of empowerment will continue at local, national and international levels and regardless of whether it succeeds in attracting governmental funding and other forms of state support.

The second question addresses the future of the traditional organisations for the disabled. The questioning of their legitimacy and role seems bound to continue and this poses a further question; whether they can adapt and respond flexibly enough to survive in rapidly changing circumstances. Again, my own view is that essentially they are nineteenth century private philanthropies turned into twentieth century state charities and that as such, they will be unsuited to the world of the twenty first century. While their demise may be gradual, ultimately they will have no role to play in a society that becomes ever more empowering and democratic.

The third question concerns the future relationship between the old and the new, Up to now the relationship might be characterised as 'benevolent hostility' but as the disability movement grows in strength and thus has the resources to campaign on more issues, it seems to me inevitable that one of the targets for such campaigns will be these traditional organisations. This

will occur both because the old will continue to be seen to be living parasitically on the ideas of the new as well being in direct competition for scarce resources.

This raises the fourth question which focuses on the relationship between government and these differing organisations. Again as governments attempt to modernise themselves along the possible lines of a written constitution, proportional representation, changes to the House of Lords and even republicanism, more modern forms of voluntary activity are likely to be supported. This will ultimately mean that the decline of the old organisations will eventually become terminal.

These questions, then, are directly related to the implications of the growing power of the disability movement. Few analysts or observers have taken seriously the disability movement as a political force and if they have mentioned it at all, usually it has only been in passing. One recent commentator on disability policy does however, attempt to address the significance of the rise of the disability movement, albeit from a North Atlantic perspective.

"What is significant about activism of this sort is that it is intended to be a counter-hegemonic political response to handicapping rather than a legal institutional response. The difference between a demonstration in the streets and a lawsuit may seem to be merely a matter of strategy, but we should not lose sight of the fact that there is a difference between an attempt to destigmatise a group through political empowerment and an attempt to seek specific legal remedies for an individual.

(Bickenbach 1993.171)

This confrontation with dominant social order, he suggests, represents revolutionary rather than reformist political action. For me, the emerging disability movement in Britain is neither one thing nor the other; in fact it is a movement which incorporates both revolutionary and reformist politics. My own evaluation of its significance reflects the partisan position I outlined at the beginning; that is that the disability movement is not only important to disabled people. It is increasingly becoming important to everyone because

" . . . the disability movement is moving inexorably to the centre of the stage, and its significance lies not in the legacy it will leave behind, but in the new forms of social relations it will be instrumental in creating".

(Oliver 1990.93)

As I suggested at the beginning of this paper, all this is significant not just to voluntary organisations in the disability field but for the voluntary sector as a whole and indeed for democracy, within which voluntary organisation has a key role to play. As we move into the twenty first century we are likely to see the struggle for voice intensify right across the voluntary sector. This will coincide with the opening up of our political institutions to include many of those individuals and groups previously excluded with the fundamental changes that will bring in its wake.

Taken together, this will mean that our democratic institutions in the twenty first century will be very different from what they are now and that the new voluntary sector will be crucially concerned with giving voice to their constituencies within these changed democratic institutions. As I have suggested, the only voluntary organisations who will be able to meet this challenge will be the newly emerging democratic and accountable ones.

The choice for Governments in responding to these changes both now and in the future is therefore simple; do they want to continue supporting the past or do they want to invest in the future?

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APPENDIX A

There were three main methods for gathering the information on which the study discussed herein is based; (a) the scrutiny and analysis of documentary sources including minutes and papers from the BCODP and discussions and descriptions which have appeared in the new disability journals which have risen in conjunction with the new movement; (b) in-depth interviews with 23 disabled people who have been centrally involved in the emerging disability movement; and (c) my own perceptions and understandings as I have been both an active participant in, and academic observer of, the history and contemporary struggles discussed herein.

In choosing the people to interview, we did not use random, quota, snowball or any other form of sampling. Instead we contacted people who we knew would have useful things to tell us. Inevitably we were not able to interview everyone we would have liked to but we hope our choice does justice to the silent many as well as the vocal few. Most of those contacted agreed to be interviewed, a few refused for a variety of reasons, and some sent written comments instead. We do not claim that the book will therefore be an objective account of our recent history, but a description and analysis of some of the issues that face us as we continue our collective struggle to self-organisation and collective empowerment.