Talk to the Scottish Disability Equality Forum
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by

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Cabbages of the world unite

My own introduction to the disability movement was in 1980, when I began to work for DIAL UK. One of my first tasks was to read a paper co-authored by Ken Davis at the 14th World Congress of Rehabilitation International in Winnipeg Canada.

At this Congress, Rehabilitation International published its own Charter, the central aim of which was to call on participating governments to take all necessary steps to ensure disabled people had full integration and equal participation in all aspects of the life of their communities

However, at the same congress, the Executive of Rehabilitation International turned down an amendment to its constitution, proposed by the Swedish delegation, that disabled people should comprise 51% of its ruling body

All hell went loose when this decision was announced. There were approximately 200 disabled people at the conference from America, Australia, Africa, Asia - everywhere, even the backwaters of Europe. No-one could understand the duplicity of these doctors, social workers, and officials from governmental and non-governmental bodies who comprised Rehabilitation Internationals Executive at that time

That night was electric. Disabled people congregated in a side room at 11 pm. There was no organisation, no format for the meeting, no leadership - just an angry mob of disabled people talking in groups and milling around the room. Then Ed Roberts got on the stage. Ed had poliomyelitis and at that time Reagan had not yet kicked him out of his job as Director of Rehabilitation for California. Puffing on his oxygen cylinder, as if he were Harold Wilson, smoking a pipe, he greeted the noisy rabble, by crying out - 'Cabbages of world, unite!'

There was such an uproar of acknowledgement and then all went quite whilst Ed spoke about the need to develop a separate international disability movement.

Those few disabled people organised themselves there and then to draw up their own constitution and began to agree strategies and structures before going to bed at 4 am in the morning utterly exhausted.

I had never felt, nor have since, the galvanising energy which came from such a hungry angry mob of disabled people. They had come from the four corners of the world and they were in no mood to be cast aside by a load of quacks and pen-pushers. In the middle of all that fervour, I felt I was in the middle of the Russian revolution, or battling down the doors of the Bastille. The common identity and sense of outrage towards such a demeaning decision and perverted rationale was so great that it drove us to work throughout the night without the remotest feeling of tiredness or awareness of the battles which lay ahead

That was the beginning of Disabled People's International, which now fosters the disability movement world-wide, promoting independent living in countries whose cultures are as diverse as India and Honduras.

Back in 1980, those activists in Winnipeg went home to many different societal cultures and political systems. Some went back to countries where disability services, were minimal and heavily medicalised. Others went home to a society which saw disability as a civil rights issue, where equal opportunities and control over one's own personal decision making were paramount. But no matter what culture or what political structure existed within the country, those activists worked to the same principles and philosophy which are the essence of the disability movement today.

I went home to a culture and a society which predominantly saw disability in terms of the medical model; where disability was seen in terms of personal tragedy; and where highly organised charitable effort was the main response.

However, I was working with a set of disabled people who saw disability as being socially constructed. In fact, like Bob Findley's work on 'housing disability' my paper in Winnipeg talked about 'information disability', rather than 'physical disability', or 'learning disability'.

In other words, it is not my cerebral palsy which creates my disability but the structure of society - its built environments, negative attitudes and discriminatory organisations and institutions.

I went back to a Britain where this debate was live. Where small groups of disabled people were beginning to take control not only over their own lives but over the services which supported them - housing, information, transport, personal assistance. I went back to a Britain where an even smaller group of people - those within the Union of Physically Impaired Against Segregation - had created the basic principles of the disability movement but were still working to promote them

As well as this, I went back to a British disability voluntary sector, highly controlled by able-bodied people, who were preening themselves for the International Year of Disabled People (IYDP). I, for my sins, was on RADAR's (Royal Association for Disability and Rehabilitation) organising committee. Now, for all the garden fetes and back slapping that went on during IYDP, among the establishment of organisations **for** disabled people, the year did have a significant effect on organisations **of** disabled people. It did politicise many disabled people into forming action groups and coalitions - in fact, several DIAL groups formed themselves into coalitions and one or two into CILs (Centres for Independent Living). IYDP also gave a spirit to the formation of the British Council of Disabled People.

A classification of disability organisations

But where did all this confusing mish-mash of organisations come from? Mike Oliver, one of the great thinkers within the disability movement, and himself a Professor of Disability Studies at the University of Greenwich, categorises disability organisations in order to describe their range and scope and to provide a key to their historical development.

This list of types of organisations should be viewed flexibly. It does not fit every organisation. Neither does it provide a trajectory of organisations, with the first group being the earliest and the last being the most recent. In fact, the disability movement, i.e. organisation **of** disabled people, can be traced back to 1889 with the formation of the British Deaf Association. But most of the campaigning work in the early part of the 20th Century was carried out by blind workers who twice marched on the London to demand better wages and improved conditions of employment, during the 1920's

Lets turn to Mike Oliver's classification in more detail

1) Partnership / Patronage, e.g., Capability Scotland, MS Society

The rise of the traditional voluntary sector has been linked to the rise in capitalism. By the mid 19th century, there were a number of small societies for blind people. This led to the creation of the Royal National Institute for the Blind in 1868. Similar developments occurred for deaf and physically impaired people, but always on a 'cure or care' basis. The person is either 'cured' and totally self-reliant, or 'cared for' within segregated institutions.

The church or individual rich do-gooders set up many of these organisations. If not always for the overt purpose of self-aggrandisement, many do-gooders received honours and prestige from the state and their peers, without fundamentally changing the status and conditions of disabled people

With the establishment of the welfare state, in 1948, the idea that the individual citizen would be cared for 'from cradle to the grave' was not truly realised. Instead, the state entered into partnership with the voluntary sector to maintain these segregated 'cure or care' regimes. Indeed, alongside the introduction of the welfare state, after the war there was a boom in disability organisations controlled by relatives of disabled people (misleadingly called 'carers') and other interested parties. It is interesting to note that in many instances power later moved from these lay people to professionals, once the organisation started to employ them.

Finally, it should be remembered that these organisations always define the problem to be met from the perspective of those predominantly able-bodied people who run them; and set their own criteria of success from within that same perspective

2) Economic / Parliamentary, e.g. DIG, Disability Alliance, CPAG

Again these are mostly organisations **for** rather than **of** disabled people, but a few have been organisations **of** disabled people. In fact, as an example of what I have just said about power moving to professionals, the demise of DIG as a powerful advocate of disabled people came about when the professionals it employed alienated their grass roots disabled activists, upon whom they relied for fund raising.

Returning to the economic/parliamentary type of organisations, rather than relieving distress and poverty, as most charities do, by providing direct services, these organisations usually only conduct research and lobby parliament on single issues - mostly on poverty

3) Consumerist / Self-help, e.g. SIA, DDA, CILs

These are organisations **of** rather than **for** disabled people. They are self-help organisations, providing services designed to meet need as defined by their own members. Some may also be political/campaigning groups. Others may be working in collaboration with other voluntary organisations, or local and national statutory bodies. But all are controlled and led by their disabled members

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4) Populist/Activist, e.g. DAN, British Deaf Assoc.

Again these are organisations **of** rather than **for** disabled people. These are political activist groups, often antagonistic to charities and the partnership approach of organisations in the first group of this list. Their main aim is the 'empowerment' of the individual and/or collective, consciousness raising and collective action. DAN, for example, was the group, which brought Oxford Street to a halt by chaining themselves to inaccessible busses. They also covered themselves in red paint and chained themselves to the gates of Downing Street, protesting against the recent iniquitous Pensions and Welfare Reform Bill.

5) Umbrella / Co-ordinating, e.g. Forums and Coalitions, BCODP

Again these are organisations **of** rather than **for** disabled people. They are collective groupings of people and/or organisations of consumerist and/or populist membership and based on the social model of disability. They may function at the local, national and international level working at the political level to facilitate the empowerment of disabled people by a variety of means It is within this group where I would hope the Scottish Disability Equality Forum could be placed.

A new social movement - 'Life looks different from inside a BMW'

To understand fully what the disability movement is, one has to understand the meaning of what is called 'a new social movement'. Only the last three types of organisation - i.e. organisations **of** disabled people - can be viewed as meeting all the criteria for a 'new social movement'.

Historically, and in terms of organisational endeavour, political parties have primarily achieved social change, or single-issue groups targeted at the party political system along the lines of class warfare. One of the major criticisms of such change has been that many of the protagonists have come from outside the affected population. As they climb the slippery party political ladder, or even the slippery social ladder, they become more and more remote from that population they report to represent. That is why one commentator on the work of the voluntary sector in the field of poverty has reflected, 'Life looks different from inside a BMW.'

'New social movements are 'new' in terms of being outside the political party system and class conflict. They are culturally innovative in that they come from and are part of the underlying struggle for genuine participatory democracy, social equality and social justice.

Many new social movements are minority groups, discriminated by society. Indeed, the disability movement has been described as the last civil rights movement. The slogan of one group in South Africa is 'To boldly go where everyone else has been before'

Three preconditions to disabled people's successful participation within the disability movement

Back in 1980, as part of their rationale for excluding disabled people from their membership, the Executive of Rehabilitation International issued a statement saying that disabled people were not ready to participate in the highly complicated decision-making which they had to undertake

Within many so-called 'participatory' decision-making bodies, the power has mostly rested with able-bodied people - be they the 'do-gooder', the 'carer', the 'bureaucrat', or the 'professional'. The 'disabled person' has more often than not been in the minority - the 'token crip'. Being denied the experience of even being in control of our own lives, it is hardly surprising a number of us have limited experience of being in control of our own services and political organisations.

Therefore, there are three preconditions to disabled people's successful participation within any organisation, let alone our own disability movement.

The first is we must have the capacity to exercise power. We must gain the training and experience of management and decision-making. We must learn risk-assessment and risk-management. We must develop our confidence and assertiveness and we must organise our own training to gain such learning. Secondly, disabled people must occupy roles in which power can be exercised. We must have authority and with that authority accept the responsibilities for our decisions. Finally, disabled people's authoritative roles must be situated within links and networks so that the exercise of power is effective. We must not be isolated in our little enclave of the disability movement. We need to forge links with similar groups of oppressed people and others of similar outlooks and philosophy to garner a force within society, which will turn our vision into reality.

'Non-disabled' people and the disability movement

To follow this through for a moment - as with all civil rights movements, the disability movement does need to form allies and network with others outside its membership. Black people had white people supporting them in their fight for emancipation. Women had men supporting their movement. So disabled people have able-bodied people supporting our demands for control over our own personal lives; those services, which support us and those organisations, which represent us.

One such person is Robert Drake. As a non-disabled person, he has suggested the following roles for non-disabled people supporting the movement,

- to recognise the social model
- to reflect the thinking of, rather than speak ***on behalf of,*** disabled people
- to ***empower***, rather than ***seek power*** within the movement
- to do research on ***the disabling impacts of contemporary social policy***, rather than on disabled people
- to supply resources without the attachment of any strings
- to respond to any requests (for information, etc)
- to lobby ***with***, rather than ***on behalf of***, disabled people

A conflict of values

For the disability movement to flourish in Scotland it is vital for everyone to realise the importance of adhering to these roles. It is obvious that there is a clear conflict between the value base of policies within the British welfare system, developed by able-bodied professionals and politicians, and policies within the movement, developed by disabled people.

Table 1

Values within British welfare policy	Values within disability movement
Care	Participation
Medicalisation	Policisation
Segregation	Integration
Professionalisation	Self-help
Familism	Communalism
Eugenics	Diversity
Normalisation	Self-determination
Individualism	Collectivism
Charity	Civil rights

Preistley, Mark (1999) 'Disability Politics and community care', Jessica Kingsley

These differences are both numerous and complex, but the table above gives a summery. It is clear, though, that where welfare policy values emphasise segregation, care and medicalising disability issues, the values of the disability movement promote integration, participation and the politicalisation of disability issues.

Disability Movement is based on the three elements of a new social movement

So the disability movement meets all three elements of a new social movement. As I have pointed out, it is consciously engaged in **the critical evaluation of society** and **the redefining of problems**, which constitute the first two elements of a new social movement. It also **creates alternative forms of social provision,** which is the third.

For example, the social model came from the **critical evaluation** of the World Health Organisation's classification of diseases and impairments. This led to **the redefining** of the whole concept of disability. What is more, the social model came from the thinking and debates of disabled people, ourselves. These disabled people were members of the Union of Physically Impaired Against Segregation (UPIAS).

UPIAS was started by Paul Hunt who lived in a Leonard Cheshire Home in Hampshire. He placed a letter in the Guardian highlighting the oppression disabled people found themselves under within residential care and asking if disabled people with similar experiences would write to him. Some twenty people did - and that was the beginning of the disability movement as a new social movement in Britain.

They debated and developed their thinking by sending a 'round-robin' newsletter - which later developed into their magazine, 'Challenge'. At first, the members of UPIAS could not physically meet, for they had no resources and many, like Paul, were incarcerated within institutions. Therefore, this 'round-robin' letter was first written by Paul Hunt, who sent it to another member - say Ken Davis. Ken would then make comment on it, or write something else, before sending it on to another member. Finally, the letters and papers would be returned to Paul who would draw everything together and print a paper on the subject being discussed. In this laborious way they agreed their ideas and developed what is now known as 'the social model' of disability. This model was first published in 1975, in what has now become my little red book - 'The Fundamental Principles of Disability' - and which now forms the basic thinking of the disability movement world wide.

Finally, as well as trying to reconstruct the world ideologically, redefining problems and their solutions, the disability movement, as with all new social movements, **create alternative forms of social provision** which are participative and inclusive. Within the disability movement, the development of Centres for Independent Living is an example of **the creation of an alternative form of participative social provision,** which is based on the social model of disability.

The development of the social model and its manifestation in Centres for Independent Living, not only in Britain, but across the world, from South America east to Japan, from Finland south to Australia - are examples of a disability movement, which is a truly international social movement.

Summary

And so in summary, I return from where I started - at the international level. Disabled people in Possil or Pilton, Inverness or Islay, Dumfries or Dumbarton, who are part of the disability movement, are part of an international social movement.

We may be on the periphery of the mainstream of the political system, but **we** offer a critical evaluation of society and its structures. **We** also develop **our** own services based on **our** needs as **we** see them. Finally, within this world-wide movement **we** base **our** arguments on civil liberties and the need to radically restructure systems, rather than tinkering around the edges of existing status quo, to obtain minor material benefit.

One example of this type of argument can be found in my little red book of 1975. UPIAS was arguing against the Disability Alliance who sought the increase of income benefits as a solution to poverty among disabled people. UPIAS, on the other hand, argued for changes to overcome discrimination in the labour market; to allow disabled people to earn their own income.

However, it is testimony to the disability movement in Britain that although still on the margins of the political system, the incessant drip feeding of such radical thinking as that proposed in my little red book is now influencing mainline political dogma. The idea of taking disabled people off state welfare and giving us jobs is now part of New Labour's New Deal. The idea of giving disabled people equal rights instead of unequal handouts is also part of the DDA legislation.

The disability movement is blasting a trail through the jungle of society to the Promised Land of equal rights and self-determination. In the past, we have had valiant pioneers slashing through the prejudice and bulwark of the establishment. These trailblazers have surveyed the land and engineered ways of overcoming many of the obstacles in our path.

Now it is our turn to pick up the tools and get on with the job. There is much more hacking of dead wood and shovelling of rubble and excrement to do. No doubt, we will not get to the end of the trail; and as such, our lot may not be truly fulfilling. But we must grit our teeth and get on with the job, because without us, those disabled people, who will come after us, will never achieve their justifiable place not only in their own lives, but in the life of the community of which they - like us - are rightful citizens