

Citizenship, self-determination and political action: the forging of a political movement

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I want to talk about all the three things mentioned in the title of this Conference - citizenship, self-determination and political action.

In order to talk about **citizenship**, I have to explain why I use the term 'disabled people' rather than 'people with disabilities'. The British disabled people's movement has campaigned for people to adopt a social model, rather than a medical model, of disability.

The social model of disability says that:

- the quality of our lives, our life chances, are not inevitably determined by what our bodies can't do or look like or how our minds function. Like the women's movement, we say - biology is not destiny. If I could not get a job that would be because of discrimination, not because I can't walk or because I'm a woman
- we therefore need to separate out 'impairment' - the characteristics of our bodies and minds - from the way other people and society generally react to impairment
- prejudice, discrimination, services which disempower and segregate us, a failure to use resources to create accessible environments and technology to aid communication - these are the disabling barriers that we experience
- people with physical, sensory, intellectual impairments, people with mental health difficulties are therefore disabled by the society in

which we live

- and we use the term 'disabled people' to describe what is done to us
This language politicises our experiences and it takes the focus away from our impairments being the problem and puts the responsibility onto the society in which we live

This is why we don't use the term disability to mean impairment. Instead we use it to refer to prejudice and discrimination, just as racism and sexism refer to the prejudice and discrimination experienced by Black people and by women.

A disabled person might say, therefore, 'My impairment is the fact that I can't walk; my disability is the fact that the bus company only purchases inaccessible buses'. Or, 'My impairment is the fact that I can't speak; my disability is the fact that you won't take the time and trouble to learn how to communicate with me'.

To use the term 'people with disabilities' is to define us by our impairments because here the word 'disability' is taken to mean impairment, what our bodies can't do. It robs us of the language we need to describe oppression and discrimination.

It therefore also inhibits the analysis of whether we have civil rights and what needs to happen to enable us to achieve full citizenship.

Citizenship is about what it is to be a full member of a community. There are two main parts to this:

- participation in political processes - the right to vote, to participate in political parties, to organise around particular interests and concerns, to freedom of speech
- participation in the social life of the community.

In Britain, many disabled people experience such significant barriers to citizenship that they are also denied their human rights.

We experience a number of barriers to both political and social participation:

- we may have the right to vote but many polling stations are not accessible to people who have mobility impairments; if arguments produced by political parties are not accessible to people with intellectual impairments or with visual impairments, if meetings do not have a sign language interpreter - then these are barriers to full participation in the political process. For example, in last year's general election 88% of polling stations did not have large print ballot papers available (*Access Action*, December 1997, p.2).
- if non-disabled people set up organisations to represent our interests, and we are not involved in those organisations, we are denied a voice and we experience the disabling barrier of others determining what is best for us. This is a barrier to citizenship.
- poverty is a barrier to full social participation in our communities: people with physical, sensory or intellectual impairments have a high risk of poverty and this means many cannot access an acceptable standard of living
- segregation in 'special schools', residential homes, specialist leisure provision also means that we are not able to participate in the things that other citizens take for granted. This comes about, not because of impairment but because: so-called 'mainstream' schools do not cater for children with physical, sensory or intellectual impairments; housing and support is not available to us in our local communities; local leisure facilities create physical, communication and attitudinal barriers to access.

We are denied access to full citizenship because of the disabling barriers we experience. In many cases the denial of civil rights means a denial of our human rights. To be segregated into residential homes is to be denied the human right to a family life, to the friends and relationships we choose. If we do not have control over the help we need, disabled people will in some cases be denied access to the most basic human rights of being able to choose when to go to the toilet, when to get up in the morning, when to

go out and where. They will also be denied the right to work.

It is not impairment which denies us our human and civil rights but the experience of disability, the experience of prejudice, discrimination and disabling barriers.

The focus of our civil rights movement is therefore on society; it is not on us as individuals. The issue is not our impairments, but the extent to which our society is an integrated one, the extent of social exclusion. We ask, not what disabled people can or cannot do, but what society can do to tackle the barriers to inclusion.

The question is therefore - is ours a 'civilised' society, a 'functional' society? A high level of disabling barriers, of disability, is a feature of an unequal society, and of a society which has a long way to go in the promotion of civil rights.

Self-determination

All civil rights movements are led by people who experience the particular oppression that that movement is fighting. It is, or should be, no different for disabled people. Black people's civil rights movements throughout the world and history are and have been led by black people, women's rights movements throughout the world and history are and have been led by women. Both types of movement have had allies in white people and men but it is black people and women who have 'named' the problem, the oppression and set out the demands for overcoming those oppressions.

In Britain, there has been a tradition of non-disabled people forming organisations and speaking on our behalf. However, over the last 20 years a strong national and local disabled people's movement has developed and we have tackled a number of issues around self-determination. I want to focus on just two:

- the challenge to the definitions of dependence and independence
- user participation.

Disabled people have challenged the meaning of the words 'dependent' and 'independent'. Independence is usually thought to be about doing things for yourself, being self-supporting, self-reliant. When physical, sensory or intellectual impairment means that there are things that someone cannot do for themselves, daily living tasks that they need help with, the assumption is that this person is 'dependent'. And to be dependent is to be subordinate, to be subject to the control of others.

One of the founders of the independent living movement in Britain wrote that disabled people are victims of an:

ideology of independence. It teaches us that unless we can do everything for ourselves we cannot take our place in society. We must be able to cook, wash, dress ourselves, make the bed, write, speak and so forth, before we can become proper people, before we are 'independent'.

In contrast, the independent living movement uses the term 'independent':

in a practical and commonsense way to mean simply being able to achieve our goals. The point is that independent people have control over their lives, not that they perform every task themselves. Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it.

Unless we insist that independence is not about doing everything for yourself then we cannot achieve self-determination. Independence and self-determination are about having access to the support necessary to make choices, to say what it is we need in our lives. Self-determination is achieved by tackling the disabling barriers of inaccessible environments, lack of communication and services which disempower rather than empower people. It is also achieved by taking political action.

It was people living in institutions in Britain who founded our independent living movement and who first made the distinction between impairment and disability - They said things like, 'just because I can't get my clothes off without help doesn't mean that I have to go to bed at 6.30 in the evening when the night staff come on duty'. One of the men who first articulated this now travels the world, talking about independent living - yet 20 years ago he had to ask permission to go down his local pub.

One of the most successful political actions that came out of all of this has been the campaign for 'direct payments' - in other words the payment of cash to people who need personal assistance so that they can employ who they choose to provide that personal assistance. This is instead of having to rely on services which are designed by non-disabled people, organised by non-disabled people and which often mean that the people using the service have no self-determination - they cannot choose when to get up in the morning, when to go to bed, when to go out, who provides the most intimate personal care, and so on. With direct payments people can achieve independent living, in the sense that they have choice and control in their lives.

Before going on to talk more generally about political action, I want to mention another kind of struggle around self-determination: the involvement of users of services in the development and delivery of services. This is called things like 'User participation' or 'user involvement'. There's lots of problems with this kind of activity - not least because it is usually initiated by people who set up and run services rather than by service users themselves. However, there have been lots of opportunities created for us to try to change the relationship between those providing services and those using them.

What we are trying to do is change the nature of that relationship. We want it to be a relationship based on four principles:

- entitlement - people who need support in their lives should be entitled to support and should not be at the mercy of judgements made by

professionals about who is 'deserving' or in greatest need. Entitlement can come from legislation but it can also come from service standards, charters, mission statements, and so on. The important thing is that people *know* what they are entitled to.

- social model of disability - services should be about identifying and tackling disabling barriers. They should not be about categorising people by their impairment or level of impairment, separating them out from the rest of society. The success or failure of any service should be measured by how much it enables disabled people to do what non-disabled people do.
- a needs-led approach rather than a service-led approach. The way the service is delivered should depend on what its users require in order to fully participate in their local communities, in order to promote their human and civil rights. The service should not be determined by the requirements of those who run it, services should be designed to suit users rather than fitting the users into the service.
- promoting choice and control. Setting up a relationship based on entitlement, identifying the barriers to achieving aspirations, delivering services which meet actual needs - all this promotes choice and control, and also protects people's human rights.

There are many examples of people who use services having a say in how those services are delivered. Some are:

- service users can be involved in the recruitment of staff
- they can be involved in the writing of contracts, service specifications
- and in the checking and monitoring that standards are being fulfilled

I've been involved for three years as a consultant to a project which aims to involve people with learning difficulties in deciding what services will be like. The project is run by people with learning difficulties who have had a lot of experience of self-advocacy groups. The social services and health authorities were paying for group homes and for day services and they wanted to know what it was that service users themselves wanted. So two

'speaking up' groups were set up - one called 'Where we live group' which focussed on the places that people lived in and what they wanted from housing and support services. The other was called ' what we do during the day' and focussed on what people wanted to do during the day. The Where we live group came up with a service contract for group homes which, amongst other things, said:

The service will seek to provide a home where people feel safe, happy and are not bored.

Residents can expect to:

- do things by themselves if they want to
- have a TV in their room
- get help with learning how to do things such as cooking
- go to bed at a time they choose
- go shopping when they wish to
- be quiet when they want to be.

The contract then listed things that the service would not do. For example:

Staff will not:

- point and shout at people
- bang doors
- fail to listen to people
- treat people like children.

This kind of contract is:

- more meaningful than the usual kind of service contract -which is often full of rhetoric such as 'treating people with respect' - it is more grounded in the reality of people's lives
- more measurable than the usual kind of service contract. You can measure whether staff shout at people, it's not so easy to measure vague notions such as 'treating people with respect'.

Political action

User involvement, user participation, is one form of political action aimed at changing people's daily experiences, increasing the quality of their lives, and their participation in their local community. It therefore has an important role to play in furthering disabled people's human and civil rights.

There are various other forms of political action which have the same general aims. Perhaps the most important is the setting up and running of our own organisations. We cannot achieve civil rights without this, indeed running our own organisations is an important civil right in itself.

Yet historically, it is non-disabled people who have spoken for us. In Britain, there is a long tradition of this - and of people earning large sums of money, being elevated to the House of Lords, being given high status in society - all for doing things which have resulted in disabled people being locked away from the rest of society.

We have had to struggle against the tradition of charity: a tradition which treats us as objects of pity, as tragic individuals, whose quality of life is inevitably so poor that sometimes it is seen to be not worth living. Help is given by people who do it to feel good about themselves, so we are expected to make the gift of our gratitude in return for them providing what they think is good for us. There is no room for self-determination or civil rights within the charity model.

In recent years, many disabled people have started to use direct action to bring the attention of the public to our concerns, and to challenge the stereotype of us as passive recipients of charity. We successfully stopped an annual Telethon which raised money by various silly stunts, and by presenting disabled people as tragic objects of pity. The slogan 'Rights not charity' says it all - although others, such as 'Piss on Pity' are also quite useful.

A form of direct action which reversed the charitable relationship was used last year when a group of disabled people gave out money to passers by to pay for the cost of writing to the government demanding full civil rights.

This made a powerful contrast with the more usual form of collecting money on street corners - where non-disabled people rattle tins trying to prompt passers by to give money to charity out of pity and where the amount of money collected is determined by how 'appealing' the particular tragedy is (children dying of cancer being the most popular and homeless people the least).

But perhaps the most effective is when disabled people chain themselves to so-called public transport, thus giving non-disabled people the experience of that we have every day of our lives - of barriers to going about our daily lives in the way others take for granted.

All civil rights movements needs allies and the most effective ones are those who relate their own experiences of being disempowered to our experiences. Allies are people who identify with our experiences, who relate our exclusion and experience of discrimination to their own experiences of disempowerment. Such allies are of enormous importance to us as individuals and to the disability movement. We don't need people to do things *for* us but *with* us. It was an Aboriginal woman who said 'If you have come to help me, then you can go back home. But if you see my struggle as part of your own survival then perhaps we can work together.' Her words are as relevant to us as disabled people.

Disabled people are fighting for a society which celebrates difference, a society which does not react to physical, sensory or intellectual impairments, or emotional distress, with fear and with prejudice. We want a society that recognises the difficulties we face, but which also values us for what we are.

Our hopes for the future are based on the justice of our wish for control over our lives, the strength of our demands for equal participation, the passion of our belief in the value of our contribution to the communities in which we live. We are part of the most exciting civil rights movement in the world today.

Jenny Morris, February 1998.