

# DISABILITY AWARENESS RESOURCE GROUP SEMINAR 1989

Developing Disability Awareness in Strathclyde

*The Evolution of Disability Awareness*

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## 1. INTRODUCTION

'Disability Awareness' is not something that has been invented by experts or by disabled people. It is, rather, something that has been growing amongst ourselves over the past twenty years. 'Disability Awareness' is not about an individual becoming aware of his or her impairment (accepting or adjusting to disability). It is, rather, about a growing collective identity amongst ourselves. In my view, therefore, it is absolutely essential to make a distinction between the growth of personal awareness in a disabled individual and the development of collective awareness amongst ourselves as disabled people. In this paper I will not be speaking about the development of personal awareness, nor will I talk about 'The history of disabled people' (which still needs to be written), but I am going to concentrate on the history, or more accurately, the evolution, of an unashamed collective awareness of ourselves as 'disabled people'.

Firstly, we should all understand that no single event, such as the 1981 'International Year of Disabled Persons' made us change the way we think about ourselves. Whatever 'people with able bodies' think about their power to influence the general population's view of us, and how we might see ourselves, history (when it is fairly written), will show that we had started to change the way we think about ourselves long before people with able bodies had even become aware that a new image of disabled people might be possible. At the very best, these grand events designed by people with able bodies to help 'poor cripples' gave support to, and encouraged, changes that we were already making happen all over the world. It is these changes amongst ourselves that we ought to be studying. For it is in the knowledge of our past struggles that we can gain real confidence about our ability to think for ourselves and to change the circumstances in which we live. In the final analysis, despite the intentions of individual experts (with able bodies and progressive ideas) as a group they have a vested interest in increasing medical and bureaucratic control over our lives.

However, before trying to understand even a little about our growing self awareness it is essential for us to make sure that we are talking the same language; that we agree about the starting point for our discussion.

To me there seem to be two starting points. These are (a) that there have been important effects resulting from our much greater participation in our own communities and (b) that we are making much clearer and sharper criticisms of existing disability services. Let us look at these in more detail:

- (a) changed situation – in some very important ways disabled people have become more integrated into our communities. There seem to be three areas where this change is most notable:
  - (i) out and about: in Britain, as in all industrialised countries, it has become very rare to see disabled people on the streets, or in the shops. The policy of preventing public begging on the streets led to the provision of a wide range of special facilities which effectively removed us from our communities. However, in recent years it has become much more common to see some (still, of course, not very many) disabled people in public places (eg. you can always see some

disabled people shopping in the accessible shopping centre in the new city of Milton Keynes).

- (ii) public influence: some disabled people now also occupy influential positions in ordinary life (eg. the vice-chair of the 'Disabled Peoples International' has become a city councillor in Zimbabwe; in Sweden a former blind member of the 'Disabled Peoples International' World Council became a government minister; there are an increasing number of books written by disabled people which are being used as text books in training people who work in the field).
- (iii) public access: most non-disabled people have now become familiar with, what might be called, the 'non-threatening' aspects of disabled living, such as ramps, beeping pedestrian crossings over roads, etc. This has helped to reduce fear of the unknown and made integration much more acceptable.

Of course, overall, things have not changed a great deal for most disabled people. Only a tiny number, those better off, have benefited from the changes. Nevertheless, I think it is true to say that the changes are both real and historically significant.

- (b) service provision criticised – there is deeper and sharper criticism of services for disabled people. This has taken place at several levels:
  - (i) inadequate: there are an increasing number of reports criticising different services for disabled people. Of course, in some areas, like 'rehabilitation', almost since its conception, there have been papers about difficulties in the delivery of rehabilitation services (eg. chronic problems in establishing effective 'teamwork' within rehabilitation). Not so long ago we saw criticism of the 'Artificial Limb and Appliance Centres' and the way that they provide their equipment: The 'Royal College of Physicians' has expressed strong concern about services for disabled people in the community (not that any, to my knowledge, organisation of disabled people has agreed with their conclusions). Even more recently we have had the 'Last on the List' report about NHS services and disabled people and 'The Living Options Lottery' to add to the criticisms.
  - (ii) inappropriate: there is also, I believe, growing awareness amongst disabled people of the need to question not only the inadequacy of service delivery to disabled people but also to question some of the basic premises behind these services. The most well known, with almost universal agreement, is about the inappropriateness of medical approaches to the social problems disabled people face. In Britain the building of 'Young Chronic Sick Units' under medical control was a classic example of a massive failure in planning resulting in facilities that are not wanted. There is also some evidence (and this is growing), however, of the gap between what service providers think about the value of the services that they provide and what disabled people feel about the services that they receive.
  - (iii) professional rigidity: it also seems clear that some professions were developed to fill service roles created by the medical approach to disability. Now that we are questioning the role of this medical approach we are fast approaching the time when we may have to face up to reality, and admit, that some professions are very much out of step with our new situation. For example, 'Occupational Therapy' has taken on the role of assessing disabled people for the provision of equipment and recommending house adaptations. It has done this after it had matured into a profession, based upon medical ideas about 'therapy', in the hospital or

rehabilitation setting. Now, however, we have to ask, is it right for a profession based upon medical or para-medical theories rather than the engineering and design disciplines, to control the provision of equipment to disabled people?

Although there is wide recognition that something is wrong with services, particularly community based services, for disabled people many people seem to think that this is simply because there are not enough resources available. Attempts to solve this crisis by requesting more staff and money to do more of the same thing that is already being criticised, cannot lead to improvements. As long as services are planned and developed on assumptions, on definitions, which are not quite right then the problems with these services will remain. What we have to do, therefore, is to go back and take a clearer and deeper look at our basic understanding of disability, our understanding of ourselves, and the appropriate forms of help that we need.

## **2. BASIC ASSUMPTIONS**

There seem to be two fundamental assumptions about which we can all agree in 'disability':

- (a) real problems – disabled people do have real personal and social problems! These problems are neither the result of our denial of our so-called 'disabilities' (as so many professional workers have been taught) nor are they simply a question of changing the attitudes of people with able bodies (as many disabled people seem to believe).
- (b) assistance – disabled people need practical help in overcoming these problems.

What is particularly important to emphasise is that our self-awareness of, and definition of (a), the real problems that we face, critically influences (b), decisions about what kind of help is needed. What criticisms of existing services suggest, in my view, is that the problems faced by disabled people have been wrongly defined and therefore the type of help provided has not sorted out the problem. Let us look at the issue of help a little more closely.

## **3. HELP**

Helping other people is not a simple act. It often involves interactions between people with long term psychological and social effects on all those involved. One thing is clear. Organised, or institutional, provision of help is not a simple act with an outcome that is only limited to the time in which the help is offered and accepted. A paralysed person, for example, taught to try and walk with callipers and crutches as a way of getting to an otherwise inaccessible toilet will develop a self-awareness that can be psychologically harmful. The person may well come to believe that using a wheelchair is an inferior means of moving around and that relying on this form of mobility makes them less human than others. With this in mind we must think about 'help' much more carefully:

- (a) type of help – there are nearly always many different ways to solve the same problem, depending on how the problem is defined. For example, a person with a visual impairment may need to get information from written sources. One way could be to provide a person who will read the information to the disabled individual. Another approach might be to provide reading glasses. In both cases the objective can be achieved but there are obvious, and profound, implications in the specific types of help offered.
- (b) how help is provided – the decision to provide the visually impaired person with money (say to pay for either the reader or the glasses in the previous example), or to provide the help directly (by having a list of readers or a bag full of glasses from which the provision can be made to the disabled person) will also be significant.

Both (a), the type of help, and (b), how this is provided, will affect the relationship between helper and helped and how they understand each other. Far too little attention has been paid to this side of delivering services when they are being planned. 'Prevention', 'rehabilitation', 'equalisation of opportunities', are all different approaches to helping disabled people. They are clearly not the same. Not only is more thought needed about different forms of help but we need greater clarity about when one approach is more appropriate than another. It may seem, for example, obvious that the problems of disability can best be solved by concentrating on preventing disability. It is well worth asking, however, what social and psychological effects such attitudes may have on us and the public mind when campaigns on prevention are set up. Is prevention in fact a problem of disability, or a problem of able bodied society unable to accept disabled people? Racism, for example, could be solved by preventing the existence of different races, but is this a real alternative? The way help is planned, therefore, is extremely important in influencing public attitudes about disability.

- (c) helping relationship – this is concerned with the way in which help is designed, planned, controlled, provided, maintained, received, rewarded and appreciated, etc. It is important to appreciate that simply shifting from one type of help to another will not necessarily deal with unhappiness about certain services (eg. in Britain wheelchairs are prescribed for disabled people by doctors who are often lacking in knowledge about good wheelchair design. But simply transferring this control to, say, occupational therapists or physiotherapists, will not make disabled people less dependent upon others for help).

*To summarise:*

I have tried to show some of the basic concerns we should keep in mind when looking at services for disabled people. These are:

- (a) change – the situation of disabled people has passed a historical turning point and old attitudes, interpretations and definitions will no longer do
- (b) basic assumptions – if we are to be serious about developing new approaches to getting the right kind of help for ourselves then we must agree between ourselves what we regard as basic assumptions. In other words we must develop a collective self-awareness.

#### **4. CURE OR CARE**

Let us now look at the usual way help is offered in existing services for disabled people. Medical rehabilitation is perhaps a useful starting point because it is in rehabilitation that a particular form of help became very systematised. This has had a powerful influence on public attitudes and nearly all the services.

- (a) cure – in the first instance the label 'disability' comes to mind when an individual with a bodily or mental impairment who is not functioning normally, from birth or later in life as a result of an accident or disease, comes to the attention of a helper (usually a medical worker). Disability, therefore, becomes conscious in the mind of the helper as a facet, or personal possession, of an individual. The objective of this primary helper (the doctor) is to cure the individual's problem and return him or her to normality. Successful treatment means a return to normality and elimination of the personal disability problem.

The aim of returning the individual to normality is the central foundation stone upon which the whole rehabilitation machine is constructed. If the disability cannot be cured normative

assumptions are not abandoned. On the contrary, the aim of treatment now becomes 'to be as normal as possible'.

It is because of this, over-emphasis on normal behaviour, that all aspect of daily life get interpreted as having therapeutic value to disabled people. The result can be endless soul destroying hours of exercise trying to approximate able bodied standards by, for example, learning to 'walk'. In rehabilitation even leisure activities, such as 'sport', ceases to be a pleasure and is imposed as a therapy. Most disabled people, like most people generally, are not mad about sport. There is neither anything wonderful or specially meaningful in the sight of disabled people playing sport (fanatically chasing the air-filled skins of animals!). Rehabilitation philosophy emphasises physical normality and, with this, the attainment of skills that allow the individual to behave as close possible to able bodied behaviour (eg. only using a wheelchair as a last resort, rather than seeing it as mobility aid for disabled people, like a pair of shoes is a mobility aid for people with able bodies).

- (b) care – the emphasis on being and behaving as normal as possible can condition helpers (voluntary or professional) to think very narrowly about disabled people and the lives we can lead. Given that a disabled person cannot be cured the degree of normality achieved assumes great significance in the minds of people who are helpers. The logic of rehabilitation is that the closer the person gets to being normal the more we are thought capable of living in normal society; the further away from normality the greater the degree of care considered necessary.

There are two ways in which this logic gets reinforced. Firstly, at the 'practical level'. Because work (employment) has been designed by people with able bodies for people with able bodies it is no surprise that those who are not of normal mind and body cannot manage and are forced to rely on personal care services (for example, it is easy to show that those with mobility impairments cannot use public transport, able bodied mobility aids, and that therefore we cannot do our own shopping and so have to rely on others to care for us). This real difficulty in coping with the world designed for people with able bodies can reinforce the view that if there is no complete cure then the degree of normality achieved during rehabilitation decides what degree of care will eventually be needed (hence the powerful incentive for people who are rehabilitation workers, with their medically orientated philosophy, to try and follow disabled people out of the hospital, and half-way schemes, into the community with their so-called community based rehabilitation). This logic also explains why people who are professionals keep on trying to measure us ('the degree of disability') - they think this tells them something about the degree of care that is needed.

Secondly, at the 'psychological level'. Because rehabilitation places great emphasis on being as normal as possible it seems natural for disabled people to aim for as normal a social life as possible. However, as disabled people do not look or behave normally, and the real possibility of a normal social life in a world designed for people with able bodies is limited, it is assumed that the only way of sustaining life, after rehabilitation has done whatever it can, is by providing care. Because this definition of disability (as a functional abnormality) is so strong in the minds of people who are rehabilitation workers they often cannot think of other ways to interpret the problems that we, disabled people, face.

Once the emphasis in rehabilitation shifts from seeking a cure and making the person behave as normal as possible, to looking at how much care and professional assistance is needed, there is a powerful incentive for the person who is a practitioner to make working with disabled people easier by convincing us to think along the same lines. There is, therefore, great emphasis amongst rehabilitation workers to 'brainwash' patients into adjusting and compensating, etc., for their disabilities. Patients who have been successfully conditioned

into accepting the unacceptable (rehabilitation assumptions) will themselves be motivated to be as normal as possible because the only, most undesirable alternative in their self-awareness, is to be dependent upon others for care. Behind this state of mind is the hidden but ever present threat of being forced into the ultimate form of care, the residential institution. From the 'cure or care' point of view the ground is prepared for building institutions, such as Cheshire Homes. The 'cure or care' approach is a powerful force in the charitable side of human psychology.

I am arguing here, that the 'cure or care' approaches to disability are very closely connected and systematically developed in the philosophy of medical rehabilitation (or its vocational and community based rehabilitation derivatives). For example 'The Chronically Sick and Disabled Persons Act' 1970 (CSDP Act) was designed to help disabled people in the community. However, at its heart, it applies the medical definition of disability to life in the community. Its starting point is that when a complete cure is not possible then what is needed, for the individual to survive in the community, is personal care. The consequence of the Act was a massive growth in the number of jobs and independence of able bodied carers and an increase in the dependency of disabled people upon this form of help.

*Cure or care forms of help:*

The 'cure or care' mental picture of disability has a long history and, in this respect, it is the traditional way of viewing the needs of disabled people. I think the following characteristics can be identified in the 'cure or care' approach:

- (a) personal – disabled people are regarded as needing constant personal help in overcoming the problems that they face (hence impairment, disability and handicap are usually defined in personal terms). We reject this view and maintain that the help needed is social; it is a collective need of all disabled people.
- (b) abnormality – the problems are claimed to be the result of an individual's abnormality of body or mind (hence an emphasis on assessing individual functioning for access to services). Our answer is to say that the barriers we face are the result of trying to live in a world designed by people with able bodies for people with able bodies.
- (c) inability – abnormality of body or mind is interpreted as preventing individuals from doing something that is normal for their peers (hence the emphasis on 'caring' services). Our interpretation comes from our own history. This clearly shows that disabled people have a natural hostility towards community 'care' but approve of community 'support'. The former is seen as something done for and to you, leaving you permanently dependent upon others. The latter is seen as something which opens up the possibility of an independent responsible life.
- (d) piecemeal – planning for these personal care services only seems to follow after a crisis (like the need to reduce the numbers of beggars on the streets). Each new approach follows logically upon the previous, attempting only to patch up gaps which have emerged as time has revealed previous inadequacies. Over a long period of time these spontaneous responses have led to the development of elaborate services which, however, do not get to the heart of the matter. Our answer has been a growing self-awareness. We are developing our understanding about the nature of disability and demonstrating that we can become 'experts' in working out strategic ways of resolving outstanding problems and finding the route to emancipation.

## **5. MOVING ON FROM CURE OR CARE**

In making a criticism of the rehabilitation 'cure or care' approach I am not suggesting that nothing was achieved. When I became disabled tetraplegics were not living more than a few years. Now, as a direct result of this form of help I am still around, criticising the medical profession, over thirty years later! The problem, however, does not lie in these successes but that people think that these approaches can be applied in areas where they are not appropriate.

What I am suggesting here is that the implications, in the rehabilitation type of approach to help, have never been properly analysed and understood. I believe that in the late 1960s the development of new technologies and industrial materials made it possible for even the most severely physically impaired person to live independently in the community. It seems that this, in turn, brought problems inherent in the rehabilitation philosophy of disability to maturity so that the positive side of the 'cure or care' approach to help became increasingly offset by its negative aspects.

The appearance of increasingly severe disabled people living in the community was a significant change in the history of disability and will, I believe, prove to be a turning point in ending the rehabilitation 'cure or care' approach. For a start when disabled people try to get about in the able bodied designed world they are forced to see and define the problems that they face more in terms of the social and physical environment than in the abnormalities of their own minds and bodies. In looking at these problems disabled people in the community will be doing no less than their able bodied peers in a similar situation. They will seek ways of modifying the environment and behaviour of others so that the barriers to their independence are removed. When able bodied people, for example needed to travel ever more swiftly from one place on earth to another they did not think that the problem lay with their defective bodies (in comparison to birds) but they invented increasingly effective aids to help them reach higher and higher into the sky. These able bodied aids not only transformed the physical and social environment, making it subservient to able bodied manipulation, but prove that there is no limit to the possibilities of human independence. The only choice does not have to be somewhere between finding an effective cure or providing appropriate care.

Disabled people living in the community experience 'disability' differently to that experienced by rehabilitation workers in institutional settings. For us the fundamental challenge is to find ways of changing the physical and social environment so that we are no longer prevented from realising our human potential, rather than thinking of what care is needed in the able bodied world when a cure has failed to materialise. The key principle, then, as we try to move away from the mental straight-jacket of traditional concepts of disability, is to see ourselves as disabled people actively facing up to life in a world with social and physical barriers. This growing awareness amongst ourselves has already resulted in setting up our own organisations, and even our own services, all over the country, all over the world. We need now to speed up this shift in thinking from an individualistic, 'cure or care' approach to a social interpretation of disability.

## **6. A WORLD FIT FOR DISABLED PEOPLE**

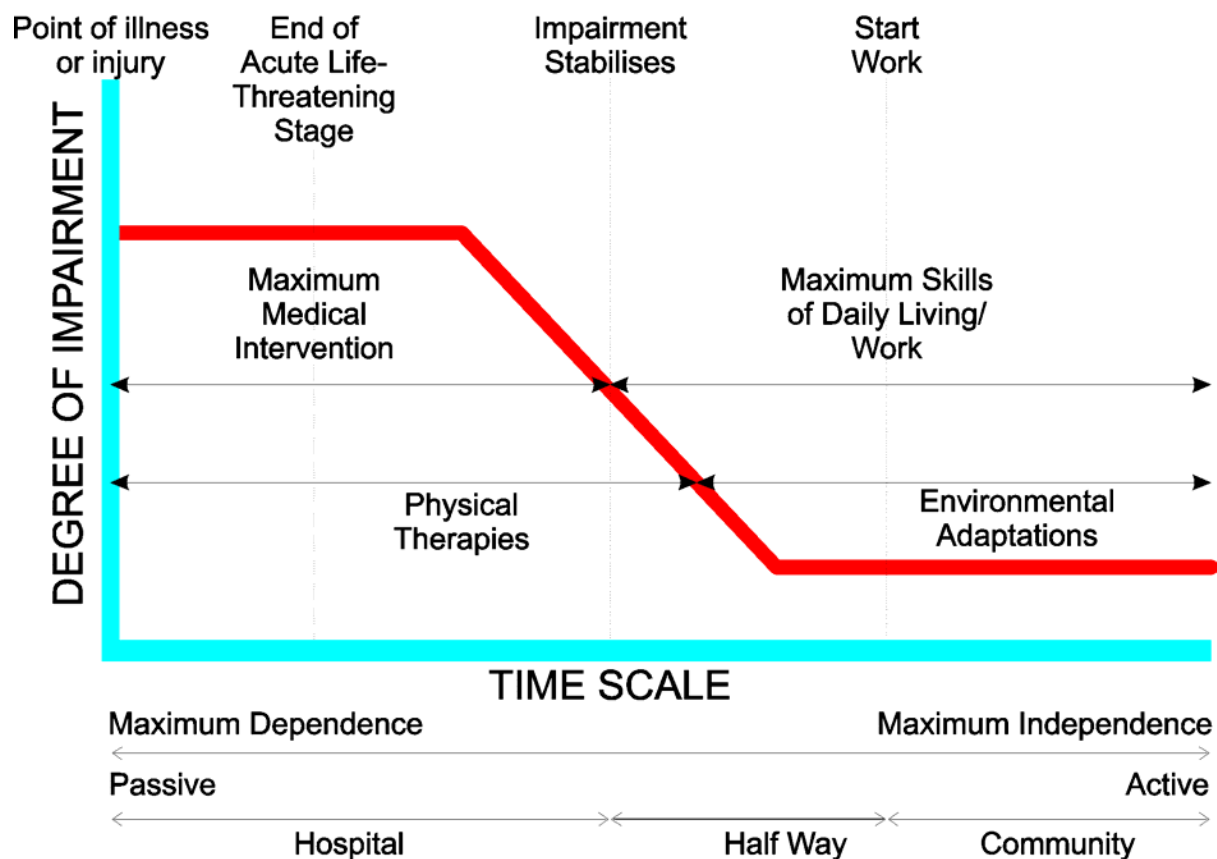
An approach which is founded upon an awareness of ourselves as social beings will encourage the development of systematic and informed planning on how to dismantle the barriers that limit the degree of integration into social life that is possible for us. This is no easy task for it means setting out to make the world fit for disabled people. It means abandoning the far easier and more flattering approach in which professionals with able bodies and other helpers with able bodies invariably try to mould disabled people into images of themselves.

Given the long history of disability our developing self-awareness still needs to be cultivated with care and understanding. No doubt both greater study and the development of a disability culture will be needed before our impact on society will become irresistible.

*To summarise:*

- (a) rehabilitation as a time limited activity (see diagramme below) – I have suggested that in the rehabilitation service disabled people are expected to progress from hospital back into the community and that the overpowering tendency of the rehabilitation professional is to try and follow them. Despite the justifications of medical and paramedical workers that they are pursuing a more holistic approach by developing rehabilitation services in the community I have tried to show that in fact they are moving the boundaries of the ‘cure or care’ approach into wholly inappropriate areas of disabled people’s lives. The first principle, then, as advocated by the ‘Disabled Peoples International’, must be to make rehabilitation a ‘time limited’ approach (the hospital period and part way into the half way schemes in the diagramme below). This, drawing boundaries around the limits of rehabilitation, is a vital stage in defining disability in non-medical and paramedical ways.

### THE REHABILITATION PROCESS



- (b) collaborative approaches – I have tried to show that new approaches to disability can arise when disabled people are directly involved in defining and planning and draw upon our own experiences (which are different to the traditional disability helpers). The best way forward, therefore, is for professionals to accept the principle of working ‘collaboratively’ with disabled people. This will not only change the power relationship in a psychologically more constructive direction but encourage a new



awareness amongst professionals about the different ways of understanding and defining disability.

- (c) integrated living services – a social definition of disability is concerned with the removal of physical and social barriers which prevent us, the disabled population, as a whole, from participating in community life. It also provides a conceptual framework for moulding the world according to our own perceived needs. This approach does not ignore the importance of assisting the individual to acquire the personal and social skills needed for a life as a disabled person. But, rather than focussing on ‘independent living’ as a way of being as normal as possible (and thereby both ignoring and denying the dependent nature of modern societies), the social approach builds on an acceptance of human interdependence and thereby sets out to find a way of integrating disabled people into the support systems of modern society. From this point of view the principle is to aim at involving disabled people directly in the planning, staffing, running, etc., of the disability related services. This will not only give disabled people more jobs, and at least contribute towards solving one of the major problems, but also provide a context for disabled people to develop a more meaningful social existence.
- (d) support systems – I have argued that the ‘cure or care’ approaches are closely linked to rehabilitation philosophy. A social approach to disability will not aim at more, even if efficient and effective, community ‘care’, but it will rather aim at the creation of a new ‘support’ system. The planning and establishment of a systematic support service, which will replace the personal care system, will be founded upon the principle of enabling and facilitating the greater involvement of disabled people in their own lives. This embryonic system is already being shaped in the ‘Centres for Integrated Living’ (often called ‘Centres for Independent Living’, but not to be confused with the independent living programmes run along traditional lines by rehabilitation workers) that are being set up and run by disabled people in this country and all over the world.
- (e) legislation – the final requirement in helping to make the world fit for disabled people is to ensure that the shift in power relations between disabled people and their able bodied peers is socially accepted. This will require new legislation which recognises the principle of disabled people controlling their own lives through their control of the support systems which enable them to live in the community.

As a final word I should say that all the elements for a new understanding of disability are already present in our society. All that needs to be done is for this to be put together into a comprehensive plan for the development of a community based support system. I am sure that this is not long in coming.

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