

Chapter 10 (in 'Exploring the Divide', edited by Colin Barnes and Geof Mercer, 1996, Leeds: The Disability Press, pp. 173 – 193).

BREAKING DOWN BARRIERS

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INTRODUCTION

In July 1995, the North West Regional Health Authority (NWRHA) published *Breaking Down Barriers: Guidelines for Purchasers of Health Services for Disabled Adults aged 16-64 with physical and sensory impairments* (NWRHA, 1995a). The development of these Guidelines took over 18 months and this chapter aims to describe that process and discuss some of the issues raised.

Breaking Down Barriers is a short document, the main part of which comprises 12 Guidelines, brief comments, and actions that purchasers should take. The Guidelines are backed up with a Companion Volume which includes more detailed comments, an extensive bibliography, information from the initial consultation, and details of the members of the strategy group. The Guidelines are targeted at health service purchasers, that is, Health Authorities and GP Fundholders.

The Guidelines were developed by a strategy group and edited by ourselves. Members of the strategy group included disabled people, some of whom came from disabled people's organisations and some of whom were purchasers and providers of services, and a group of non-disabled people who were providers and purchasers of services for disabled people. The chairperson of the strategy group was David Ackroyd who was Project Manager (Community Care) for the North West Regional Health Authority and also the Project Leader. Judith Emanuel was the co-ordinator of the project, working for the Regional Health Authority on a freelance basis.

The work on the guidelines started in 1993. It was an initiative which began under the auspices of the then North Western Regional Health Authority which covered the area of Lancashire and Greater Manchester. In April 1994 the Regional Health Authorities were re-organised and the North Western and Mersey Regional Health Authorities merged. The resulting North West Regional Health Authority was the organisation which published the

Guidelines and was responsible for monitoring their implementation although any ongoing monitoring or development work has, from April 1996, fallen to the NHS Executive, North West Office.

BACKGROUND TO DEVELOPING THE GUIDELINES

The impetus for developing Guidelines came from national directives. The Department of Health issued Guidance to Health Authorities which identified overall objectives but did not assist purchasers to think about the actions they needed to take to meet them. In 1992 the National Audit Office gave guidance on targets for some services which have been built into planning guidance and corporate contracts. Officers at the Regional Health Authority had noticed, however, that the information returned in corporate contracts indicated that these issues were not being adequately addressed by purchasers. The development of Regional Guidelines was an attempt, therefore, to give purchasers support to address these issues.

The brief given to the consultant was refreshingly unusual. There were few preconceptions about what the Guidelines would eventually look like. The concern was about process so that an important part of the outcome would be as wide an ownership of the Guidelines as possible. From the outset it was recognised that while the Regional Health Authority could put some pressure on purchasers and providers to address the issues, the impact would be substantially increased if the pressures were also coming from other directions. So one of the purposes of the consultation was to develop awareness amongst disabled people about how the purchasing process works in the hope that they would then feel more able to influence it.

The design of the process for developing the Guidelines was influenced by people from disabled people's organisations from the very beginning. The project leader and officers from Greater Manchester Coalition of Disabled People (GMCDP) discussed it prior to the recruitment of the consultant and they were offered the opportunity to tender for the work through their consultancy agency but decided this was inappropriate.

The initial discussions with GMCDP were influential. The project leader initially proposed that the consultation should ask disabled people, their carers, service providers and purchasers about what they thought of services as one group. GMCDP suggested that disabled people should be consulted separately from the other groups and drew attention to the power imbalance between the various interest groups. As a result it was decided that the

consultation should be with three separate groups: disabled people as users of services, purchasers of services, and providers of services.

The other major impact that the early discussions with officers and the chairperson of GMCDP had on the design of the project was around our thinking about carers issues in the Guidelines. Over recent years the role of unpaid carers has received considerable public attention. Pressure groups have vigorously campaigned for carers needs to be recognised, social scientists have published research about carers (for example, Finch and Groves, 1983), and government policy has encouraged health and social services departments to consider the needs of carers when providing or purchasing services.

Originally the Guidelines were to address the needs of disabled people and their carers. The GMCDP representatives were very concerned that the needs of disabled people and carers should be considered separately. Our lack of knowledge of the disabled people's movement perspective on carers may reflect the way carers needs have been highlighted by campaigns, research and policy when compared with the absence of publicity given to the independent living movement promoted by disabled people. However, we have become very aware that amongst many academics and professionals there is an absence of awareness or lack of willingness to be aware of this perspective. We think it is, therefore, worthwhile to go through the discussions which we had so that all readers can understand how we reached the decisions which we adopted. (See Morris, 1993, ch. 3.)

We understood from our discussions that the disabled people's movement reject the commonly held view of carers because it is based on people being dependent. They do not consider that independence is based on the tasks people can do but by the degree to which people have control over their own lives. We were told that people in the disabled people's movement think that the high profile of carers can be explained because non-disabled people are more likely to perceive their situation as similar to carers than to disabled people. Furthermore even if the concept of carers was accepted, it neglects the fact that many disabled people are also carers as parents, partners, children and friends.

These ideas were new to us and made a lot of sense. We realised that we had been influenced by a policy agenda which grouped disabled people and carers together and a research agenda which is concerned about the autonomy of a disadvantaged group, carers, who are mostly women. This helped us to recognise the potential conflict of interest between carers and disabled people and that the assumption that they were both users of

services for disabled people was patronising towards disabled people. A member of GMCDP likened it to consulting men about women's health services.

At the same time it is well recognised that while the majority of health service care is carried out by unpaid carers these same people have increasingly been acknowledged as having health and social care needs as users or consumers. This emphasis on carers as consumers of care is central to the philosophy of the National Health Service and Community Care Act, 1990.

It became increasingly clear to us that, with the advent of the split between purchasers and providers of services, unpaid carers need to be viewed as providers. This is not to diminish in any way the parallel acknowledgement that carers, like health service staff, have personal needs of their own which also require to be addressed by purchasers. However, as this was not the prime purpose of this project we made the decision to consult the carers as providers.

THE INITIAL CONSULTATION

As the project began under the auspices of the former North Western Regional Health Authority the initial consultation took place in Greater Manchester and Lancashire with five separate groups. The method of consultation was individually negotiated to ensure that it was most appropriate to the particular circumstances of each group.

- A contract was agreed with GMCDP jointly to organise and run a consultation day with the project co-ordinator. The day was targeted at disabled people from the Greater Manchester area, which included, but not exclusively, GMCDP members.
- West Lancashire Association of Disabled People (WLAD) have a research project looking at the impact of the Community Care Act. They are interviewing a number of disabled people at set time intervals to measure this. It appeared most appropriate to commission a report from WLAD based on the research rather than organise a separate event.
- The project co-ordinator worked with members of Ethnic Disabled Group Emerging (EDGE), a Manchester based black disabled people's group, to develop consultation meetings for members of the group.

- A meeting was held for purchasers which included people from health service commissioning agencies and social services. Attempts to involve GP fundholders were unsuccessful.
- Two meetings of providers were held which included providers from voluntary and statutory agencies, unpaid carers and people from pressure groups. The pressure groups, which included Community Health Councils and voluntary organisations run by non-disabled people, were somewhat anomalous among providers. We were concerned that they should not speak for disabled people but neither were they providers. By running separate workshops within the provider strand we felt we could accommodate them most appropriately within this group.

The model for consultation presented us with the opportunity to target specific questions to the three groups. We wanted to know from disabled people what they saw as their health needs. The purchasers were asked what influenced their decision making. If we understood the forces driving the purchasers we hoped we could link these to the needs identified by disabled people and make it easier for purchasers to act. From providers we wanted to know what made them responsive to purchasers so that we could frame the Guidelines in ways that would make the contracting process effective in influencing change where this was necessary.

Representatives from pressure groups were asked what they could offer disabled people and purchasers in order to get a sense of their potential role. Unpaid carers were asked about their own health needs related to their roles as carers. While the carers welcomed this, having identified carers as providers this was not, in hindsight, the appropriate question to ask them. To be consistent we should have asked them what would have made them responsive to purchasers and providers as by that time it was clear that if carers needs were to be addressed this should be done separately. Although there was a carer on the strategy group, issues from a carers perspective were not further developed after the initial consultation.

At the end of the consultation period we had information: from disabled people's organisations on the needs of disabled people; from purchasers about the driving forces in their decision making; and from providers that might help us to understand how they respond to purchaser's directives. There is insufficient space to give a detailed account here but it is available in the Companion Volume to the Guidelines (NWRHA, 1995b, ch.3).

We were particularly pleased with the consultation process because it did mean that we were only asking disabled people about their needs and we were asking purchasers and providers how best to make the system work to meet people's needs. This seemed to be what consultation should be about but rarely is. Certainly many of the providers and purchasers were surprised at the nature of our questions and had to think a lot about how to answer them.

THE MEMBERSHIP OF THE STRATEGY GROUP

In the initial design of the project it was decided that at least 50% of the membership of the strategy group should be disabled people. This was seen as reaffirming our commitment to the principle that disabled people should have the central role in developing the Guidelines. We were also keen that there should be a fairly even distribution between the number of people involved as purchasers, providers, and disabled people who were users or potential users of services. Care was taken to select members who came from different geographical areas and who represented as wide a range of interests as possible.

Each of the disabled people's organisations involved in the initial consultation was invited to select two people to be members of the strategy group - a responsibility for which they would be paid. Other disabled people involved included a Health Authority member, an officer of a purchasing authority and a member of staff from a provider organisation, the National Centre for Mental Health and Deafness. A comment on the subject of payment to participating disabled people is important. While it is acknowledged that there is a place for voluntary involvement in the health service, a principle behind this project was that the expertise of each participant should be equally valued. Since most members of the group participated as part of their regular (paid) employment, it was essential that disabled people who were not there in a capacity for which they were paid should also have their contribution recognised financially.

Other members of the strategy group included a Chief Executive from a Family Health Service Authority, a GP fundholder, a Consultant Physician in Rehabilitative Medicine, a Carer, a purchaser from Social Services, a Community Care Co-ordinator in a Trust who was also an occupational therapist, a community physiotherapist, and an officer from a voluntary organisation.

One of the issues that emerged early on, not surprisingly, was whether purchasers would be able or willing to find the financial resources necessary to deliver what we recommended. Whilst no assurances could be given it was significant that the strategy group believed that much of what needed to be done had little or no financial implications. There were two main reasons for this. First, it was felt that some resources were currently being wasted on services or equipment that were not what disabled people needed or wanted. Second, it was argued that so much depended on the attitudes of health service staff which, if addressed through training and other in-service means, could make a radical difference to access to services. The need for all members of the strategy group to believe that they could make a difference was critical to what followed.

DEFINITIONS AND TERMINOLOGY

The first task of the strategy group was to attempt to reach a consensus about definitions and terminology. It may not be surprising to readers of this book that this was by far the most contentious and most difficult task of the whole project. We naively assumed that definitions would be agreed at the first meeting. While we were certain from the start that the Guidelines should have a social model perspective we were unprepared for the variety of interpretations of both the medical model and the social model which were presented by a group of 18 people, albeit representing different interests.

The discussions did not include reflections on the relationship between impairment and disability - as explored in Liz Crow's chapter (four) in this volume. This subject did come up, however, when the group were working on a definition of health. The definition agreed was 'health is a state of physical, mental, psychological, and spiritual well-being free from unacceptable (unnecessary) pain or stress' (NWRHA, 1995b, p. 3, expanding on the well-known definition promulgated by the World Health Organisation). For some members of the group, however, it was crucial that the definition of disability related exclusively to social issues. This was understandable given their agenda to secure recognition of the way in which the structure and organisation of the health service disables people who have impairments, an issue that has hardly been addressed.

There were two main starting points. They were the definitions agreed by the British Council of Organisations of Disabled People (BCODP) and those agreed by the World Health Organisation (WHO) and used in the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980). It will be clear from other chapters of this book that there are people

who will argue that both of these definitions reflect a social model. Our experience was that the professionals on the strategy group were not as attached to the WHO definition as some of the medical sociologists who have contributed to this book. Conversely, the GMCDP representatives in particular were completely committed to the BCODP definition of disability.

The disability theorists reject the World Health Organisation definition as a social model. They argue that the World Health Organisation definition of the word 'disability' focuses on the individual as being problematic, requiring change to or by the person. In contrast the definition of the word 'disability' which has evolved from the disability movement focuses on society's approach to enabling people to participate in an equal way. Therefore, the decision about definitions was crucial. The Guidelines were to advise purchasers of services for disabled people. The definition would determine what the Guidelines should address. The principle was accepted by the strategy group that the definition should be one that was acceptable to the disabled people in the group.

Terminology was an equally important and contentious issue. The words we use make us think about meaning and the impact of our actions on, and our attitudes to, other people. There were two groups of disabled people on the strategy group who could not agree with each other on terminology. While people from GMCDP preferred to use the term 'impairment - where part of an organ or mechanism of the body is unable to function fully', the profoundly deaf members of the group felt the word 'impairment' has a negative meaning and should be rejected. They preferred to talk in terms of 'difference'. They emphasised cultural and language differences rather than the existence of an impairment. However, 'difference' was unacceptable to the GMCDP members because it was regarded as too general and did not classify the functional range which is the basis on which oppressive societal and individual attitudes are formed. As no consensus could be reached, it was agreed to use the word 'impairment' but to include a statement outlining the deaf member's perspective.

The following definitions were agreed:

Impairment: occurs where part of an organ or mechanism of the body is unable to function fully (while recognising deaf member's preference for the term 'difference'.)

Disability: occurs where society is structured or organised in such a way as to prevent or restrict activities being undertaken or potentially being realised because of an impairment.

A Disabled Person is someone who has a physical, sensory or mental impairment (or difference) and who is as a result prevented from undertaking a range of activities because of environmental or attitudinal constraints imposed by societies or individuals.

Access was defined as referring to a fully accessible society. This included addressing all barriers which could be physical/ structural/ environmental; emotional/ psychological; communication/ information; and financial.

One consequence of adopting these definitions was to confirm that the Guidelines would be addressed to the totality of health provision and not exclusively to that part of the service which is concerned with a person's impairment. The Guidelines also highlighted the needs of disabled people for using health facilities as parents, relatives, or friends of other users, as well as the needs of disabled staff.

Controversy about terminology continued throughout the project both inside and outside the strategy group, including objections from a local MP to some of the terms used during the final consultation.

THE GUIDELINES

Twelve guidelines were identified and each included actions that should be undertaken by purchasers to meet them.

1. Adopt the definition of disability and impairment.
 - a) Adopt this definition as a basis for all purchasing decisions by Health Authorities and GP fundholders.

The members of the strategy group all felt that purchasers in the Region should adopt the definitions that we had identified. The reasons for this varied from the positive, that they were the best consensus that could be reached, to the negative, nobody wanted to go through the lengthy process of agreeing new definitions! However, it has to be acknowledged that the process of arriving at a set of definitions was itself very constructive, if difficult.

2. Assign lead responsibility for action on purchasing of services for disabled people to a single senior manager.

- a) Assign lead responsibility to a senior manager.
- b) Establish a monitoring group of disabled people whose first task should be to set achievable targets.
- c) Establish arrangements for reviewing and monitoring contracts.
- d) Ensure that details of the targets are written in future purchasing plans and corporate contracts.
- e) Liaise with GP fundholders to develop a corporate contract.

Although a number of health authorities who commented had some concerns about how this would fit with their organisational structure, we could not come up with a satisfactory alternative which would ensure that responsibility would be clearly allocated. This guideline does however indicate the commitment to involving disabled people in the purchasing process.

- 3. Endorse the principle which places the individual disabled person at the centre of service planning.
 - a) Approve these principles as a basis for all Purchasing decisions.
 - b) Seek agreement with providers to include commitment to the principles in all contracts.

The principles underpinning the guidelines borrow heavily from the 'Living Options' principles (Fieldler and Twitchin, 1992, p.2) and concern choice, consultation, information, participation, recognition and autonomy (see NWRHA, 1995b, p. 11). The principles are significant in informing the philosophy and process underlying the development and delivery of services. It was therefore important to the strategy group that, just as purchasers were expected to use the agreed definitions, so they should work with these principles and use them to improve provider practice through the contracting process.

- 4. Involving disabled people from disabled people's groups in influencing strategy and decision making at all levels.
 - a) Establish links with local disabled people's groups including black disabled people, disabled women and disabled lesbians and gay men on action that would be relevant to ensure that services are more appropriate to their needs.
 - b) Encourage participation in influencing strategy and decision making by publicising the process for involvement e.g. through Local Voices.
 - c) Ensure that the practical arrangements for involvement are inclusive in terms of access arrangements, valuing people's time etc.

- d) Jointly with disabled people identify and develop contracts for a minimum of three services by April 1996

A number of issues should be addressed by taking these actions. It establishes the heterogeneity of disabled people and that links with different groups within the disabled community need to be established if all the needs are to be identified. It also establishes that disabled people are part of the wider community and should be encouraged to participate in broader consultation initiatives. 'Local Voices' is a strategy for consultation with the whole population of a District (NHS Management Executive, 1992).

The third action concerns making participation practical. A considerable amount has been written about the importance of encouraging consultation and how to do it, both of populations in general (see, for example, Guideline 7) and disabled people in particular (Bewley and Glendinning, 1994; and Lindow and Morris, 1995) but there has been little guidance on how to put the product of consultation into action. The fourth action aims to encourage practical action based on consultation and was inspired by the Greenwich Empowerment Project (Morris, 1994) which involved disabled people in identifying four services for which they would like to recommend service specifications. Disabled people then worked alongside the commissioning agency and the Trust to develop the specifications.

- 5. Ensure that all disabled people have the same access to health services as non-disabled people.
 - a) Agree a five year programme of audit and inspection of premises and other facilities to identify disabling features.
 - b) Negotiate with other organisations to participate in the audits.
 - c) Negotiate a programme of action with all the providers and include this in their contract.

Despite the fact that a definition of access had been agreed which included information communication, emotional and psychological access as well as physical access, this guideline was worded to mean access in rather a narrow sense. It is appropriate, however, that the initial guidelines are largely concerned with ensuring that the services provided are what disabled people want and that this guideline is about guaranteeing that they can physically use services. This should cover their own requirements as health service users, as well as in all the many other ways that people need physical access to health services - for example, as workers, visitors and to support friends and family using the services.

6. Require provision of relevant and appropriate information about services in written and aural formats which are accessible.
 - a) Decide what information needs to be made available directly from purchasers and through providers.
 - b) Develop information on who is responsible for providing specific services for providers and disabled people.
 - c) Agree a strategy for information dissemination which covers sources, formats and content.

This guideline is concerned with a second aspect of access within its broader sense.

7. Contracts should ensure that different professions within the health service and across agencies co-ordinate effectively.
 - a) Ensure that Health of the Nation (DoH, 1992) initiatives address the needs of disabled people so that they can fully participate if they wish.
 - b) Identify priorities with disabled people for areas where appropriate multi-disciplinary arrangements are unsatisfactory and reach agreement with Statutory and Voluntary Agencies about how they can be addressed.
 - c) Ensure contracts and/ or service specifications specify the need for multi-disciplinary assessments where appropriate.
 - d) Ensure monitoring covers effective co-ordination and working across organisations.

This guideline is written in 'professional speak' but does attempt to address issues which cause great frustration to service users. Whose responsibility is it to provide which service? Do the service providers work co-operatively and in support of the service user or competitively and often with only secondary consideration to what the service user wants?

The processes involved in the actions here continue to encourage the consideration of the needs of disabled people within the context of implementation of policy targeted at the whole population (Health of the Nation, DoH, 1992), as well as policy targeted more particularly at provision for disabled people (Community Care).

8. Require a programme of staff training to develop awareness and action on disability issues among Purchasers and Providers.

- a) Involve local disabled people who are accountable to organisations of disabled people who will participate in the design and delivery of disability awareness and action training programmes.
- b) Identify specialist courses and elements that should be included in other programmes.
- c) Arrange for all purchaser staff to participate in disability awareness and action training and monitor the identified actions.
- d) Negotiate with providers a programme of awareness and action training to cover all employees, incorporate this in contracts and monitor the identified actions.
- e) Adopt a policy of positive action towards the recruitment of disabled people and negotiate similar arrangements for providers.

This guideline proposes actions to involve the widest range of staff in purchaser and provider organisations. The objective was that disability issues do not become the exclusive concern of people with specific responsibilities but of everyone within the organisation. It clearly states that local disabled people should have a central role in the design and delivery of training and that positive action should involve recruitment throughout the work organisation. Thorough implementation of this guideline could lead to the development and implementation of a large number of action plans throughout all sectors of health service organisations.

9. Provide appropriate and accessible health services to black and minority ethnic disabled people.

- a) Obtain local information on the types and incidence of relevant diseases and health related needs.
- b) Ensure that training programmes for purchasers and providers include awareness of the needs of black disabled people.
- c) Ensure that counselling and advocacy services which are acceptable and accessible to black and minority ethnic disabled people are available, as well as to deaf people who are culturally deaf.

The representatives from EDGE, the black disabled group who participated in developing the strategy were very clear that they wanted a separate guideline to consider the needs of black disabled people. The group expressed concern that the needs of black people become marginalised when they are combined with the needs of other multiply oppressed groups. The guideline reflects the fact that EDGE has less concern about social and medical models and over-riding concern that whatever is provided for white people is made appropriate for black and disabled people as well. The deaf people involved identify themselves as culturally deaf and therefore part of a

minority ethnic group with similar needs to other minority ethnic groups. They were therefore keen to see their needs addressed here.

10. Ensure that there are effective arrangements to provide appropriate services for people moving from children's to adult services.

- a) Identify, in conjunction with other agencies, those young people reaching the transition period in each year.
- b) Establish a formal review mechanism to assess the ongoing needs of each person with the primary objective of removing as many as possible of the disabling features of health provision.
- c) Negotiate contracts with providers that specifically refer to the needs of young people at the transition period.

Guidelines 10 and 11 are driven primarily by the professional agenda and the agenda of pressure groups run by non-disabled people. The emphasis, however on implementation should be centred around support for young people to take responsibility for themselves and the use of mainstream services.

11. Assess disabled people's medical need for services in relation to their impairment and determine how appropriate services should be provided to meet these needs.

- a) Negotiate arrangements with relevant providers to ensure a social model of service delivery which includes putting the disabled person at the centre of those services and the planning for them.
- b) Estimate the need for medical services which relate specifically to impairments within the District.
- c) Review provision and the way it is provided in consultation with disabled people and providers. Identify priorities to improve appropriateness of services.
- d) Negotiate with other purchasers where it is apparent that it will not be economic to provide the services on a single District basis.

This guideline is particularly significant in terms of what it does and does not address and how. It is clear that the role of medical services for a person's impairment should be very specific and clearly delineated and that the majority of the health needs of disabled people should be met through mainstream services.

If the guidelines had been more concerned with function, for example the way impairment was defined, then it is likely that this would have been one of

the first guidelines and the other guidelines would have concentrated on medical issues and come from the standpoint of professionals. For example, the concern about access might have been about rehabilitation and there would have been greater concentration about the medical needs of particular groups of disabled people with impairments, for example, the need for services for people who are brain injured.

12. Make arrangements to ensure that the intended outcomes from the purchasing strategy and the action taken on this Guidance actually do occur and that they remain relevant to disabled people.

- a) Use clinical audit structures, protocols, research and development, national initiatives and biennial reviews of the purchasers role in implementing these Guidelines.
- b) Ensure that the network of disabled people and their organisations play an active part in these reviews.
- c) Ensure that all parties are able to engage in a critical appraisal of progress and relevance by employing an external facilitator to oversee the review.

Again this guideline illustrates the integration of the involvement of disabled people while using the existing organisational framework.

COMPARISON WITH OTHER STRATEGIES

We were interested to see what differences there were between the Guidelines published by the NWRHA and elsewhere and to analyse the factors which might have influenced the differences. Three elements of the guidelines were analysed; definitions used, membership of the groups who produced the guidelines, and the issues prioritised. In particular we were interested to see the degree to which the totality of health provision was addressed and whether or how carers needs were taken into account.

Five different documents were analysed. Two were from Regional Health Authorities - South East Thames (1991) and Northern (1993); two were from Joint Planning Groups, St Helens & Knowsley (1995), and Southern Derbyshire (1987); and the other was from the British Society of Rehabilitation Medicine (BSRM, 1993). 'Furthering Abilities', a strategy which was recently produced in St Helens & Knowsley (1995) used the definitions proposed in Breaking Down Barriers. All the others used WHO definitions including the British Society of Rehabilitation Medicine (BSRM, 1993) in its 'Advice to Purchasers: Setting NHS Contracts for Rehabilitation Medicine'.

Details on who developed the documents vary. Southern Derbyshire Joint Planning Group produced their strategy in 1987. There were 18 members of the group most of whom were from the Health Authority. It also included members from the local authorities and voluntary sector including one person from the Derbyshire Coalition of Disabled People and one person from the Derbyshire Centre for Integrated Living. There are no specific details about the membership of the St Helens and Knowsley Group but it does state there were people from the Health Authority, several local authority departments, the Community Health Council, the Local Medical Committee, service providers and a local Action Group. There are no details at all about who wrote the South East Thames Regional Health Authority Document, but the Northern Region document was written by three public health doctors, a social scientist, an epidemiologist and a Health Needs Assessor. Two consultants wrote the British Society of Rehabilitation Medicine document, one in Rehabilitation Medicine and one in Acute Services Planning.

It would appear that there is a range of people who may be identifying the needs of disabled people. While all the documents are concerned to promote independence of disabled people in principle, most of the guidance produced by the two Regions and the British Society for Rehabilitative Medicine concentrates heavily on 'provision to `restore and maintain physical and psychological function' (SETRHA, 1992, p.64). In contrast the documents from Southern Derbyshire and St Helens & Knowsley encompass a very wide variety of issues reflecting their production by a range of agencies.

The key issues identified by the St Helens and Knowsley document are information, transition, access, supporting independence, equality and joint commissioning, both for disabled people themselves and their carers. The South Derbyshire document is valuable because it brings together a very wide range of interests. It includes personal assistance and access issues which are likely to be high on the agenda of disabled people's organisations. It also includes carers needs in the form of respite care and training and the more professionally led needs such as rehabilitation.

Guidelines or strategy documents, provided they receive support from the agencies on behalf of which they are produced, will inevitably be a compromise of the interests of the people who develop them. Disabled people's organisations had a relatively strong influence in the development of Breaking Down Barriers compared with the other documents considered here. The disabled people's organisations main priorities were, firstly, to agree a definition of disability which was based on the way society is structured and organised and secondly, to develop Guidelines which would

improve the way health services are structured and organised in the interests of disabled people. We believe that it is this emphasis that has led to *Breaking Down Barriers* being a fundamentally different type of strategy document to others that we examined.

CONCLUSIONS

The Guidelines received considerable support notably from both disabled people's organisations and the Department of Health as well as purchasers and provider organisations. David Pilgrim (1996) has provided a useful analysis of where the agendas of social movements and public service commissioners meet in the current political situation. He describes how commissioners need alliances with consumers against the old professional elites. These alliances take the form of user involvement and participation. New social movements, of which the disabled people's movement is one, focus strongly on the role of personal experience and identity which fits relatively easily with this role. He explains that some of the interests of service commissioners and disabled people converge. This would appear to explain why it was possible to develop the Guidelines with the definitions that were agreed and the proposed actions and achieve support from both commissioners and disabled people's organisations. Where there was criticism or concern about where the Guidelines were heading it came, not surprisingly, from some clinicians. The review of guidelines developed elsewhere as well as the way *Breaking Down Barriers* was received indicates that purchasers are open to a wide range of influences in terms of the development of services for disabled people at this time.

There were several points at which the project could have failed to progress. First, it was a much larger project than had been originally envisaged and the extra resources that were required might not have been available. This included the availability of the consultant to carry through the work to its conclusion. This 'largeness' of the project had two dimensions. It was very much more complex than originally envisaged and it took a great deal more chronological time (i.e. from start to finish). Undoubtedly getting a group of professionals together would have made it simpler and shorter. However, it would not have contained, either within the process or the output, anything of the richness we believe emerged from a genuine effort to hear what the recipients of services actually thought and needed. We did not want tokenism but real participation and this proved costly in terms of both time and money. We are convinced, having completed this work, that the real cost of effective participation is usually underestimated by purchasers and providers alike.

A second reason why the project might have failed was because the strategy group made very slow progress for a considerable time. This was partly because of the time it took to agree the definitions and therefore to be able to develop a sense of what the Guidelines would be about, partly because of our reticence to stop consulting about every detail and begin to commit ourselves to paper with draft documents, and partly because of the dynamics of the strategy group. The diversity of the group made all this essential because everyone concerned had to feel secure and to believe that this was a genuine partnership with a commitment to an outcome that had the potential to make changes to practice within the Health Service.

The methodology used for developing the Guidelines enabled the following to happen. A disabled people's organisation, GMCDP, played a key role in identifying that users, providers and purchasers should be consulted in separate groups. This meant the needs could be identified by disabled people and the focus of the consultation with providers and purchasers was how to use contracting to meet those needs. GMCDP's influence also ensured that disabled people were seen as the service users, and carers were seen as providers. The central role of disabled people on the strategy group led to definitions and terminology being agreed which were strongly influenced by their views. This played a key part in ensuring that the issues addressed were predominantly about access in its widest sense to all health services and that the 'divide' explored throughout this book was at least partially bridged in *Breaking Down Barriers*. We believe that, if purchasers and providers enter into real dialogue with local disabled people, the Guidelines can form a foundation on which to build better and more appropriate services in many cases with little or no additional ongoing cost.

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