

# Papers from the conference Community development in health: addressing the confusions.

held on 13 June 1984 at the King's Fund Centre

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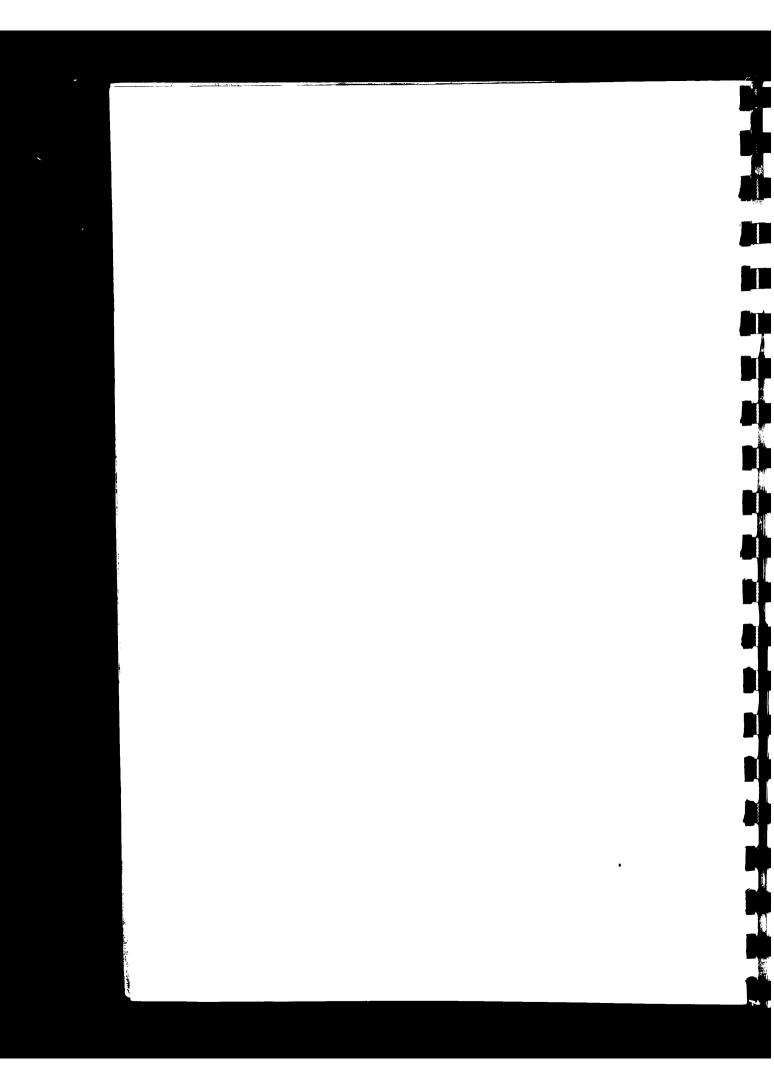
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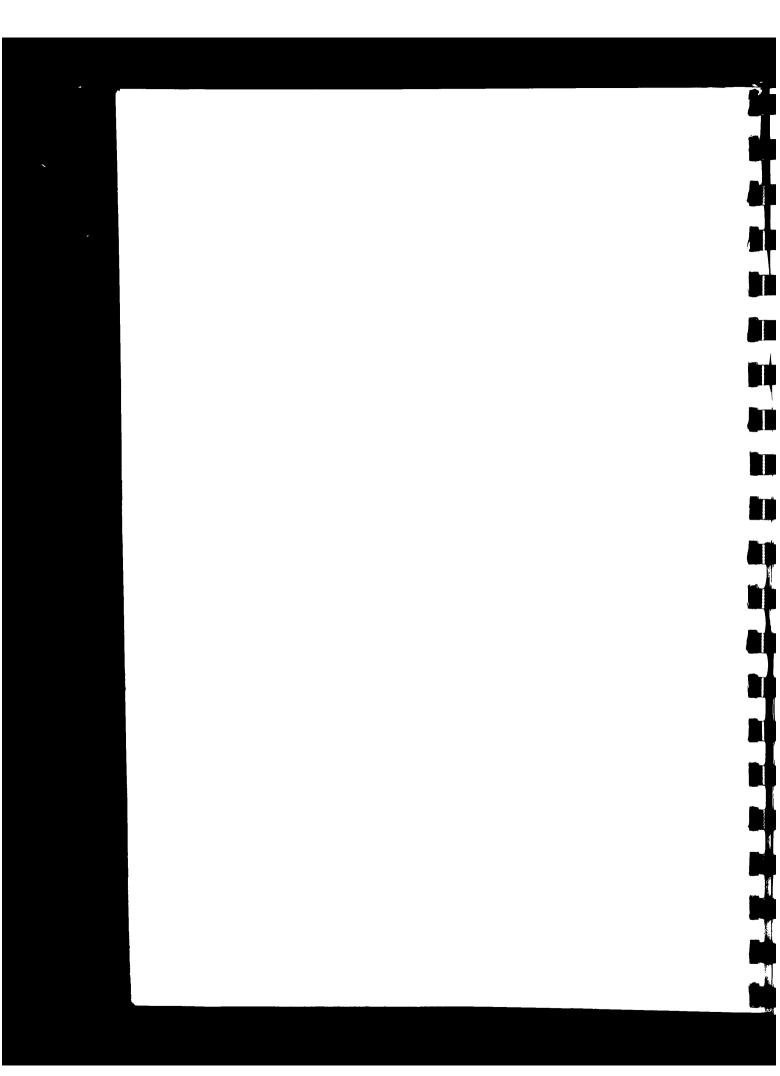
PAPERS FROM THE CONFERENCE 'COMMUNITY DEVELOPMENT IN HEALTH: ADDRESSING THE CONFUSIONS'

Held at the King's Fund Centre on 13 June 1984



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'Community Development in Health: Addressing the Confusions' was a one-day conference held at the King's Fund Centre on 13th June 1984, organised by the London Community Health Resource and the Community Health Initiatives Resource Unit, in collaboration with the King's Fund. This report is a collection of the papers given during the morning session, which was chaired by Sir Douglas Black and attended by over one hundred people. These included health authority members, health professionals and officers from grant-making trusts.

This was the first major conference on community development in health since the King's Fund conference in 1979. During the intervening five years, community development in health has become established as a movement in its own right, with many new initiatives emerging up and down the country. The need to hold a major conference on community development in health arose from the work of LCHR and CHIRU with local initiatives, from which it became apparent that many key personnel and decision makers, both within and outside the Health Service, were unclear about the nature of community development in health and the role of community health initiatives in the provision and planning of health care. In addition, the project workers - many of whom were nearing the end of their funding - felt an urgent need to present and explain their work more widely to potential funders. The first task of the conference was, therefore, to address some of the confusions and complexities which exist around community development in health.

This conference also set out to show the importance of community development in health in enabling people to define their own health needs and to participate in planning health services. The World Health Organisation's 'Health for All' strategy underlines the value of individual and collective public participation in shaping health care. A key question is how this can best be achieved in the bureaucratic and highly professionalised structure of health services in Britain. When resources fail to keep pace with rising demand, appropriate strategies are needed to improve the quality and relevance of local health services while maintaining public support for the NHS.

Although community development is something which rarely happens within the framework of the NHS, this report shows how partnerships <u>can</u> be developed between providers and users of services. It also shows how front-line professionals can support the aspiration that people should achieve greater control over their own lives. Community health initiatives – although often modest in scale – have a wider significance for many of the major challenges facing health and health care in Britain today. One of the many such challenges which the conference set out to address and which is featured in this report is how, in an increasingly divided society, inequalities in health and access to health care can be countered, particularly for the black and ethnic minority communities.

In attempting to address the confusions and complexities about the community health movement, however, it is important to examine the context in which community health initiatives have to survive. Measured against the scale of the challenge they face, the investment has so far been small. Most community health projects to date have endured a hand-to-mouth existence, relying on short-term funding - mainly from Urban Aid through health and local authorities, and from charitable trusts. While this may have advantages in promoting innovation, it is less than adequate for supporting the long process of community development in health. The insecurity of short-term funding means that a substantial amount of time and energy goes into raising funds rather than into essential work.

Additionally, there is often a requirement for such initiatives to evaluate their work. The evaluation of community health work, examined in this report, is a complex and often difficult area: community development by its very nature is not well suited to the application of rigid epidemiological techniques which are often demanded in the health field. Although the need for evaluation is recognised by projects and funders alike, it is likely to be possible in only the most enduring projects. There is therefore an urgent need for existing funders to reconsider their practice of short-term funding for community health work, and for new sources of funding to be established.

It is hoped that this report will provide a useful insight into current thinking on community development in health, and its role in influencing the health and health care of people in comtemporary Britain.

A more detailed and descriptive account of community development in health from the workshops held during the afternoon session of the conference is given in Community Development in Health: Addressing the Confusions by Gwynne Somerville (King's Fund/LCHR, 1985, £3.00). This report outlines the work and experiences of a number of local health initiatives.

# COMMUNITY HEALTH INITIATIVES: CLARIFYING THE COMPLEXITIES WITHIN THE COMMUNITY HEALTH MOVEMENT Alison Watt

A great deal of confusion exists about the nature, variety and extent of community health initiatives. This paper attempts to clarify the picture by drawing a definitional framework. The framework will be of use to people in their attempts both to understand the movement, and in identifying those particular aspects in which they are most interested.

This process of clarification means exploring a number of apparently divergent paths before arriving at the stated aim. In order, however, to even begin to make sense, it will be helpful to offer an initial description. A community health initiative (CHI) is any group of people who meet together to tackle a health concern that they hold in common. Some of these groups also have the explicit aim of attempting to influence health service provision. As an example, a group of pensioners who meet in a community hall to learn more about their bodies - particularly within the ageing process - and who might also campaign for a reduction in heating bills would be described as a CHI.

This brief description is itself insufficient. It fails to tackle questions and uncertainties about the origin of CHIs, their staffing, management, points of reference to health professionals, status, validity - and so on. However, given that the Community Health Initiatives Resource Unit knows of at least 10,000 such initiatives in existence across the country, perhaps the most manageable way to begin is to consider what a CHI is not.

# Community health in the National Health Service

Within the National Health Service (NHS) the term 'community health' has a specificity that is not mirrored in the community health movement. Therefore departments of community medicine and community health service units are not  $\underline{\text{formally}}$  connected with the movement.

There are, nonetheless, individual community physicians, health visitors, district nurses and other health professionals who in various and often substantial ways support community health initiatives. This might involve helping to establish an initiative, becoming a member of its management group, or providing input to the running of a health course or programme. Whilst these instances are important models for the strengthening of relationships between the statutory and voluntary sectors, the point to be made is that community health initiatives are not institutionalised within departments of community medicine and community health services units.

Departments of community medicine are concerned to use the principles of epidemiology to identify relationships between different sectors of the population and particular illnesses, as attempts to measure and meet the needs of their local communities. Similarly, community health service units are responsible for the delivery of health services that are located within each district's community. Community physicians, health visitors, district nurses, and community nurses are the health professionals responsible for implementing the programmes and services generated by the departments of community medicine and the community health services units. Health education officers may also be based within the district's community health services unit, and a number of health education units are concerned to develop practices of community-based health education.

### The issue of need

Community health initiatives take as their point of departure from NHS community health the issue of need. Whilst the complexity of need is acknowledged, the difference in the approach of CHIs to need is that the group's own assessment of its needs is the foundation for both its existence and its rationale. The assessment of need within the NHS is normative - that is, health <u>professionals</u> decide upon the definition and priority of needs. This process is upheld by a set of beliefs which state that health professionals possess knowledge not available to the lay population, and are therefore best placed to be the assessors of needs. Conversely, people in community health initiatives place a high priority on the <u>subjective</u> recognition and validation of needs, and take this level of assessment as the base-line for any subsequent action.

It can be seen therefore that the community health movement adopts a fundamentally different philosophical approach to health. It challenges the notion that an expert is required before a need can be recognised and validated, and it therefore addresses health issues and concerns that health professionals have either failed or decided not to address. The potency of this challenge to expert-defined need is the existence of 10,000 community health initiatives. There are, therefore, 10,000 groups across the country attempting to meet sets of needs that are not provided by the NHS, and that are sometimes not even recognised. It is because of this essential difference in approach to health that the majority of community health initiatives are not institutionalised within the NHS. This is not to state that they have no place in the NHS. Indeed, there is a strong argument that CHIs can offer the NHS both assistance in the process of defining needs, and in the nature of the delivery of health care. Meanwhile, it can nonetheless be seen why the large majority of community health initiatives are currently located within the voluntary sector.

Before moving on, the picture is further complicated by the various meanings attributed to the term 'voluntary'. Frequently, the voluntary sector is regarded as an unpaid army of philanthropists, attempting to do good with soup tureens, tea and sympathy. Whilst such activities have their value, it is important to dispel the notion that the voluntary sector is principally philanthropy. In summary, the voluntary sector is non-governmental, and provides non profit-making services directed towards the relief of poverty, distress, and hardship - in any of their manifestations. A few points worth stressing are that workers within the sector are usually paid, they are often professionally trained, and the services they provide are not necessarily free.

# The community health movement and its manifestations

We can now turn to consider in more detail what exactly a community health initiative <u>is.</u> It has been summarised as a group of people meeting together to tackle a health concern they hold in common. The thousands of CHIs that have been identified clearly constitute a popular movement. There are, however, many different sorts of initiatives. The majority are informal, unconstituted, and small. 'Community health initiative' is therefore the generic term for any group within the community health movement. It was a combination of the movement's size and diversity that prompted the conceptualisation of the following categories. The categories are flexible and can overlap.

# Self-help groups

The first category, self-help, is perhaps the most familiar. It can be subdivided into three.

- (a) Self-help groups that exist to deal with the consequences of a medically recognised and well-provided-for disease, or disability, such as diabetes or deafness. Here, the function of the group is one of mutual support in those areas that fall outside the remit of professional care. So whilst this care might well be adequate within its own boundaries, people have sets of related needs which can best be met by other sufferers rather than by a health professional.
- (b) Self-help groups that have formed in response to relatively poor health care for medically recognised conditions. Examples include anorexia and tinnitus. These groups often adopt a pressuring function, calling for more research into the condition and, perhaps, for a destignatising of the condition.
- (c) Self-help groups that tackle bodily states that are known to be bad for health - such as obesity and unfitness. These groups tend to be more spontaneous and transitory than groups in the other two sub-divisions, yet are well supported by health professionals and fall within the emerging concept of health promotion.

Most self-help groups will be started by a sufferer, a relative of a sufferer, a health worker, or will be prompted by a local or national voluntary organisation. Some will be quite well organised, will meet regularly, and might engage in fundraising activities. The bulk, however, will be informal, very small, and run entirely on and by the participants' own efforts. It is in this latter section where we find the greatest overlap between self-help groups and community health groups in structure, the difference being that in self-help groups there is a recognition by professionals of the illness or disability.

# Community health groups

Community health groups exist to tackle health problems that are regarded as being beyond the scope of medical practice. Whilst many health workers recognise the effects that housing, race, income, diet, occupation, gender and so on can have on health, many feel there is nothing they can do about these variables. So thousands of groups have sprung up to tackle the roots of health problems. There is in these groups the feeling that, for example, getting a drug for a skin irritation caused by substances at work is not going back far enough in the chain of the cause of the irritation. So, in this case, a group may be formed in the factory which will aim to persuade management to ensure that handling of harmful substances is safe. At the same time, the group would spread the word to other workers about how to protect themselves, and about their rights.

Similarly, women living in the same balcony of a housing estate may be concerned at the council's slowness in coming to attend to reported repairs. The women might choose from a number of options about how best to persuade the council. They might write a joint letter of complaint, they might go to the Tenants Association, and so on. Whatever they decide to do, they feel they are taking some action, and hence feel more in control of their circumstances. This sense of control is, in itself, beneficial to health.

It can be seen that these groups are quite informal, and can start in a completely spontaneous way. Sometimes they cease to exist when the task in hand is solved (if it is) and sometimes another issue is picked up. Sometimes the group will exist completely independently of any statutory support or prompting, and sometimes a health visitor, social worker, or occasionally a GP will be involved.

### Community development projects

These initiatives are much smaller in number. What makes them different from community health groups? Firstly, they will almost always have one or more paid workers. Because of this, they will last for longer, and they will usually be bigger. Secondly, there is a commitment within community development to the principle that people should have access to the decision-making processes in the public sector. It is acknowledged that people in disadvantaged areas, who are usually working class, are denied a voice. In short, are kept powerless.

Community development is defined by a Working Party of the London Council of Social Service as:

'The process by which an open-ended intervention is made in a locality to assist groups of residents to clarify and deal with problems that the local people themselves have identified. Such a process is concerned to assist in achieving social change in the area of social conditions and institutions. The work involves several different stages: defining the problem; identifying causes; formulating solutions; and finally mobilising resources to seek to effect the necessary change'.

The relationship between community development and health is one of inequalities and health. It is becoming more widely understood that the inverse manner in which health relates to social class - that is the lower the class the higher the morbidity and mortality rates - can be attributed to factors that have hitherto been considered to be beyond the medical remit. The practice of community development, with its concern to address inequalities, locates health firmly in the arena of social production. Health, therefore, is regarded as a collective state, and one which requires collective action.

The appropriate response, therefore, to a state of health for which the individual cannot generally be held responsible, is to collectively tackle the root of the problem. If a man has recurrent bronchitis which is caused by the damp in his council flat, the solution lies in improving the damp, not in repeat prescriptions for antibiotics. Success in convincing the council to repair the flat will be dependent upon the amount of pressure exerted. There are no blueprints for success. The point to be made is that community development techniques are based on the premise that change occurs as the result of collective action in, and access to, the decision-making processes that affect the quality of people's lives.

This, of course, is the radical point of departure from the manner in which health is regarded, and subsequently provided for, within the NHS. Health is located within the individual, indeed usually only a bit of the individual, and hence is treated at that level. So whilst many medical practitioners might recognise that the man with bronchitis is failing to improve because his flat is damp, there is no mechanism within current medical practice to cure him. Gestures of despondency at the inadequacy of the housing stock are not sufficient. There can be no logic that defends the pursuit of a medical practice or ordering of priorities that are known to be ineffective

- particularly when the aetiology of the problem is understood. Hence the call by community development workers is for a re-thinking of the delivery of health care. This is no modest task, but certainly one in which community development in health has a lot to offer.

# Community development in practice

Given that the most likely point of entry by a newcomer to the community health movement will be via one of the better known and established community development projects, and given their importance in terms of their approach to health, it is worth focusing a little more sharply on to community development health projects in practice.

It has already been indicated that collectivity is the major focus of community development. Therefore, once a need has been identified, a collective solution to its resolution is sought. Usually, groups and projects that are generated through community development will have been started by either a paid community worker, or by a volunteer attached to a community or neighbourhood centre.

So the difference in the origin of these projects is that they are prompted by someone who has the specific function of attempting to enable residents of a local neighbourhood to become more involved in seeking improvements in their community, and in the quality of their lives within it. Community workers, community health workers, neighbourhood workers, and community volunteers are all people whose work is based in the community, and who will, generically, be engaged in community work. Some of these workers will be using the principles of community development. Hence, they will be concerned with assisting residents to identify and define their own needs, and then subsequently with the organisation of the chosen form of action. Community development workers attempt not to impose their own values, nor to take a leading or authoritative role. The work is centred in the understanding that residents in disadvantaged areas will only gain control by taking control - not by following a leader who decides on their behalf.

Community workers, of all types, will typically be employed either by a voluntary organisation such as a neighbourhood centre or settlement which will be in receipt either of charitable funds to develop that particular community, or from a public authority such as the social services. They will organise their work so that wherever it is possible they will be managed by a group that is composed largely or entirely of the community's residents. Depending upon their source of employment, they will be accountable either to the line manager in the public authority, or to management and/or the team of workers in the voluntary organisation.

There are also a large number of workers in different public authorities who use the principles of community development in various aspects of their work, but who are not solely community development workers. These include social workers, community health professionals, community education workers in adult education institutes, and so on. It can be seen then, that there are substantial numbers of people engaged either whole or part-time in helping people to gain control over their lives.

There is no uniform path that a person follows in order to become a community worker or a community development worker. A recent report shows that over half have had formal training in community work, other professionals such as health visitors obviously hold that particular training and have become interested in community development. Some have come to community work through voluntary activities in their community, and

some through their experiences of becoming involved in community action. Whilst it is therefore impossible to give more than an overall impression of the routes to community work, it is important to note that the work is demanding, stressful, and requires considerable amounts of energy, sensitivity, and commitment. It has its own codes of practice, and has to answer to the most exacting of managers - the people it is concerned to assist.

# Community health workers

In addition to community workers, who might during the course of their everyday neighbourhood work occasionally be involved in a group that has a health focus, there are community workers who specialise in health. These are called community health workers. They sometimes, although not necessarily, have a health training, and it is their job to help people in the locality in which they are based to both identify their health needs, and to assist them in seeking to have them met. The work that is undertaken is extremely varied – as again, people's needs are not uniform.

So, for example, if a worker is based on an estate where there is a high proportion of elderly residents, a number of them might express that they feel lonely, and that they feel they no longer know what to expect from their bodies as they change with age. The worker could then propose that a pensioners club be formed, and would test the idea with other elderly residents, and other neighbourhood workers. If the idea met with approval, a venue such as the tenants' hall would be found, and the first meeting advertised throughout the estate. Between the worker and the group, a programme of health activities and learning would be drawn up, the pensioners taking on as much of the decision-making and organisation as was possible and practicable. There are many groups such as this, although all have a different emphasis. One group in Brent, for example, in addition to running pensioners' health courses, was successful in persuading the health authority to provide a much needed and long-overdue chiropody service.

A centrality of community development health projects is the recognition of the value of the group process. The sharing of experiences and knowledge, and the discovery by an individual that she/he is not the only person suffering, thinking, or experiencing things in certain ways is therapeutic in itself. This sharing also helps to lessen the guilt people experience when ill - a guilt generated by the way in which an individual is typically held responsible for becoming ill. The community health worker will be sensitive to all of this, and will ensure that there is time for people to talk, and will encourage them to trust and validate their own knowledge and experiences. The worker will also encourage people to voice their criticisms of the health service. This forms part of the process of enabling people to have a greater say in their treatment when they do have to use the health services.

Another part of many community health workers' work is to promote, within the neighbourhood, an awareness of health issues in such a way that people can see for themselves the value in having a greater say in the local delivery of health services. Hence, some neighbourhoods might identify the prospective building of a health centre as a health facility in which they would like to be involved. Another might decide that as the local hospital does not provide adequate food for Asians, action should be taken in attempt to have this remedied.

The possibilities for involvement are endless. Some workers work only with a particular client group in a neighbourhood - such as young mothers, whereas some work in the neighbourhood generally. The issue of common concern however, is that people living in disadvantaged areas particularly experience their lives and therefore their health as something over which they have little control. It is the challenging of this state of affairs that community workers are pursuing. For of course their motivation is not one of heedless agitation. It is the realisation that much of today's medical care is both ineffective and inappropriate for people who suffer the disadvantages of our societally produced inequalities.

# Summary and conclusions

The community health movement is made up of thousands of community health initiatives. If we begin with the assumption that any community health group is called an initiative - in as much as it is new and innovatory - we can then proceed to identify various different sorts of initiatives within the movement. Calling all community health groups 'community health initiatives' might appear contentious to some, as latterly the term has tended to be used to describe community development health projects. However, there is also emerging the feeling that calling only such projects 'initiatives' imposes a hierarchy of innovativeness that is undesirable, and counter-productive to the non-expert philosophy of the movement.

The movement, then, can be seen to be composed of different sorts of initiatives which can broadly be described as falling into a number of categories. Firstly there are the reasonably familiar self-help groups which address the consequences of medically recognised illnesses, using the principle of mutual aid. They will usually have originated from a sufferer, a relative of a sufferer, a health worker, or have been prompted by a local or national voluntary organisation. Within this category is a new strand of groups, those who are keen to exercise away, or prevent by exercise, certain illnesses or undesirable states of fitness. Not all fitness and health promotion groups are community health initiatives, indeed it is becoming big commercial business. Nonetheless, there is a marked flourishing of small informal community groups across the country helping each other to improve states of ill-health.

Secondly, there are initiatives that are tackling health problems that are not recognised as of concern to the practice of medicine. There are thousands of such groups, and their distinction from self-help is that they tend to address the socially <u>causative</u> factors of ill-health, rather than deal with the consequences of an illness or a poor state of health. Hence we have our group of mothers on a housing estate balcony identifying isolation as the root of their depression, and forming a group to tackle that isolation. These sorts of initiatives can emerge totally spontaneously, or can perhaps be prompted by a health visitor, social worker or community worker.

Finally, there are initiatives that have been generated by a community development worker, where the focus is one of empowering residents in a locality to identify their health needs and to organise appropriate action to ensure that they are adequately and appropriately met.

The majority of all initiatives are located in the voluntary sector. Those that have managed to secure funding have typically done so by stitching together grants from Trusts and Foundations, and occasionally from public

authorities. Some, in certain inner-city areas have been successful in applying for Inner-City Partnership monies, Urban Aid, and occasionally joint finance between an area's local and health authorities. Funding, however, is a crucial and central problem, and one that it is essential to have resolved if the movement is to survive.

In conclusion, therefore, the community health movement has a diversity and an importance it is vital to recognise. The movement's diversity comes from its concern to address and focus upon people's own perceptions of their needs. Its importance is that it does that. There is, therefore, a tremendous amount of knowledge and experience in the community health movement which could usefully inform the practice of the NHS. To this account, it is vital that the movement is, in <a href="principle">principle</a> supported and valued. Furthermore, it is vital that in <a href="practice">practice</a>, when an initiative seeks support from the NHS or from other bodies, it is given a fair hearing.

# THE NEED FOR COMMUNITY DEVELOPMENT IN HEALTH Robert Morris

The purpose of my paper is to give you some idea of the reasons why I, as a District Medical Officer of an inner city health authority, see a need for community development in health. My starting point I suppose should be my belief in the innate right of people to plan their own health care. The World Health Organisation in its 'Global Strategy for Health for All by the Year 2000', which I feel sure many of you will be aware of and to which our government was a signatory, explicitly made the point that:

'People have the right and the duty to participate individually and collectively in the planning and implementation of their health care. Consequently community involvement in shaping its own health and socio-economic future, including mass involvement of women, men and youth, is a key factor in the strategy.'

In the developed countries version of this, the WHO European Regional Strategy - which our government also signed - this theme is shortened and becomes the 'humanisation of the health services'. It is much more concerned with ensuring adequate and acceptable health care for all. These themes of people's right to participate, of community involvement, are open to misinterpretation, and I would like to clarify my own position There is a danger, for instance, that preoccupation with a 'consumerism' approach with its emphasis on the rights of consumers, will lead to a separating rather than a bringing together of those who provide and those who receive services. Without labouring the point too much, I would add that there is a fundamental difference between the concept of consumers of material goods or services, and the concept of people as individuals or groups taking action to influence their own health. Sue Dowling in her recent book 'Health for a Change' to my mind hit the nail right on the head when she wrote that 'one reason for the health service's difficulty in reaching certain families with preventive health care may be our failure to recognise that in every consumer there is a potential provider'.

So why do I as someone concerned to see improvement in the health of the local population, support community health initiatives, and attempt (a carefully chosen word!) to get my authority's agreement to support them through the Inner City's Partnership or indeed to fund them itself either directly or indirectly? It is not easy to obtain such commitment from an authority, and I have to say at the outset that the amount of opposition from many medical traditionalists, elitists, and others frequently leaves me speechless at its open hostility to learning about and therefore dealing with the real health problems that engage so much of the energy and will of local people.

I would like to give, then, some of the reasons why I believe there is a need for community development in health. In general many of them (if not all) are to do with the present inability of a bureaucratic and locally unaccountable NHS to get close to and to understand the issues of health that concern and control people's lives. We have, for instance, no workers who can be described as being from and of the community and who can identify with it. Also, our structure for policy-making and planning does not often allow, let alone encourage, the participation of the community in the process of reviewing health issues. My reasons therefore will cover how best we can identify those real health issues; how best they are communicated to the official providers of health care services in a manner

that will make us sit up and take notice; the ability of non-statutory bodies to initiate and manage projects in the community which we in the NHS would find difficult to fit into our main programmes; and lastly, the way such projects create for themselves a means for communication between people and the statutory services on issues which are not necessarily central to the project, but which will affect people's social and economic environment in such a way that their health will be influenced positively.

# People's experience of health

Firstly, then, the ability of community development projects to relate directly to people's experience of health. Let me give some examples from local projects:

'When my husband's away from these flats, he's a different person. Once he crosses the road into the flats he gets depressed, they're so cold and damp. You can never make anything of them, they're so small. You just give up in the end. It's not the people - they're nice people. My roof's been leaking for ten years so I sleep in the living room. I have arthritis and my husband suffers with his chest and gout.'

That was Anne, a woman from one of the Stockwell estates. Here's another woman, Jackie:

'Living around here affects your mental health - you've only got to see the number of odd looking people walking about. The pubs are packed - alcoholism is a problem. That's because people live day to day. They don't have the money to live any other way. Other people look down on them so they abuse their bodies.'

Lastly, from a report on a mobile health education project about users' experiences of health services:

'Most criticisms of health services - and regrettably almost all the comments we receive are criticisms - are known to planners. However, perhaps planners do not have the access to information about the extent of dissatisfaction around whichever issue, not perhaps any bases from which to assess the accuracy of the criticisms............We do not anticipate that this recording of people's experiences of local health services will effect any marked change. If however it goes some way to redressing planners' beliefs that people under-use the health services because of individual lassitude, waywardness or ignorance, it will have served a purpose. It is quite clear.......that people under-use the health services because using them can be such an unpleasant experience.'

Before anyone starts to have possibly unnecessary guilt feelings, let me add that it was my district being referred to.

Here then I am talking about the need to get close to local people and their experiences. Why should we do this? The need is there for two main reasons. Firstly, because our 'scientific' methods of health status measurement are still in the stone age and we require all the input about people's health that we can get. What may be surprising to us (although it shouldn't be) is the potential differences between the information output of the epidemiological and professional viewpoint and that of a community

Unfortunately here, as too often happens, the development project. professional expert opinion may not be shared by those with direct Secondly, we tend to create policy and to devise health experience. programmes at a level that is too far removed from people for us to be aware of how acceptable or appropriate they are likely to be. instance, I see great difficulties ahead in 'Care in Action' policies if there is not due attention paid to the demands placed on carers in the community and their needs and desires. Likewise, there is the question of the acceptability of services. If using our services is so unpleasant, what has to be done to make them more pleasing? How do we get away from a victim-blaming approach of some health educators from whatever discipline or ensure that what I like to call the 'style' of our services is appropriate for the people concerned? The style has to fit the characteristics and the wishes of those on the receiving end, if the service is to be effective.

So here then are some reasons for having close to the people concerned a 'something' that is able to use those people's experiences, to recognise and indeed often to generate health needs. Why do I say 'generate'? Because often the 'something', the Community Health Initiative (CHI), will have the role of sensitising a local community, through discussion of people's experiences, to its particular situation, and to bring out into the open, at a level that people find comfortable, those negative health factors within the circumstances of that community.

# Power and confidence

My second principal reason for wanting community development in health is really to do with power although that perhaps requires explaining.

Most people have little confidence to deal with questions of their own How do they cope with the problem of wider health personal ill-health. The increasing reliance of people over the years on health professionals has been encouraged by those professionals. It is the function of most CHIs to enable people to learn from one another, to share problems, experiences and motives. By working through groups CHIs aim to develop collective approaches to encourage people to discover health information for themselves, to strengthen their trust and confidence in each other and the group, and to go on to use that information, that confidence, that power, to create change. In individuals that power should But in a group it cannot be. It becomes a force which not be ignored. authorities, both local and health, will find that they have to take account of. The experience in Lambeth, for instance, of a group of local people wanting to change the 'official' plans for a health centre and the group's influence in due course on those plans has been well documented.

Most of the health problems that seem to really worry people are not just within the remit of the NHS. Indeed, most seem to be due to social and economic factors. So most health issues can only be resolved in a multiagency manner, through collaboration of agencies. The community itself is often the only common element between the service agencies, and part of the CHIs role will be to recognise this and to use it. Not infrequently of course this mechanism will, and should, be used for other purposes, such as influencing the local authority to change its local policy on a matter which may well have no direct health connotation, but a very direct social one.

Much of this power aspect will be the motivation of people sufficient for them to express their views to health authorities. CHIs may often act as advocates, therefore establishing a link that did not exist previously with an authority and opening up a dialogue with it. My own experience of this, on the receiving end so to speak of a number of community projects, has been variable. Within one or two, it has been noticeable that our access to people (and presumably vice versa) in terms of learning directly from their experience, was very limited, and I felt at times that in some ways those particular projects did not fulfil my first 'raison d'etre' of improving access. It was noticeable as well in my view that these were the projects where the self-confidence of people in themselves was not sufficiently developed for them to be their own advocates, but relied instead on professional community health workers. I would be interested in discussion to learn whether other people's experience is similar to my own in this matter. I suspect it may also have something to do with how accessible and flexible an authority's policy-making and planning structure is.

# Innovation and experiment

My third reason is to do with the constraints that surround the NHS, in so far as innovation and experiment are concerned.

Many CHIs will be viewed by authorities as peripheral to their main task of providing health care. The NHS as a service orientated around sickness rather than well-being, does not react well to approaches from the community to establish new projects or new provision. Most urban districts in any case are losing resources at such a ridiculous and non-caring rate that they will inevitably be concentrating on the short-term question of priorities for safe-guarding services. The role of CHIs in being able to establish projects in the community and to demonstrate their approach to health authorities is therefore important.

In addition there is considerable flexibility of organisation as well as purpose in CHIs, which the bureaucracy of the NHS inhibits. We lack the sort of skills in the NHS for instance that are needed in community work as there is no health service professional with the training, the time and the experience to do it. Yes, I have heard of health visitors, but they will not do, and you have only to study their own literature on their function and training to understand why I say that. All our health professionals are just that......professionals with a training in a particular knowledge area, whose main attribute will be that knowledge. community development we are not really talking about the possession or lack of knowledge about health. We are concerned more with encouraging people to approach and to tackle those health issues that concern them. This then is a job for individuals who have the ability to work with others, to identify with them, to understand and not judge them, to guide and advise them on technical issues, to motivate them and to give them support. Much of that work will be in groups either pre-existing or more often needing to be established, and so there are also skills required in setting up such groups, in energising them and servicing them.

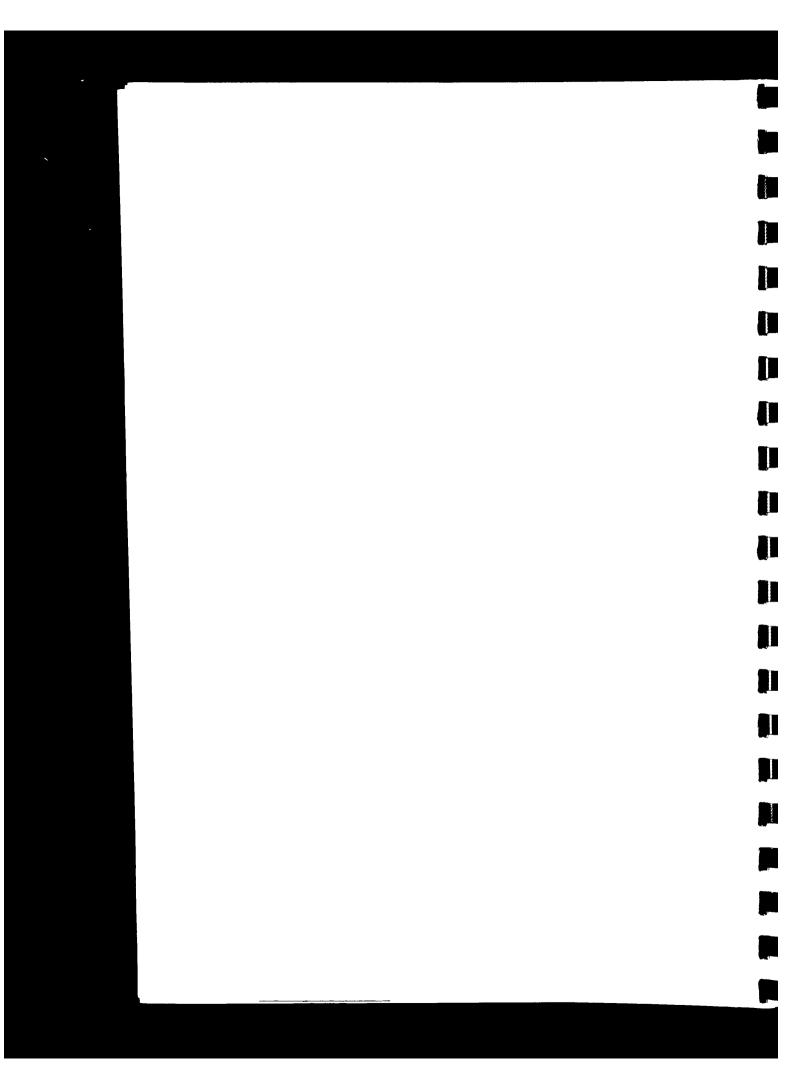
It is easier to establish such positions and to create the sort of environment for such people to work in, outside the formal structure of the NHS. In addition, the question of trust and confidence must come into the argument. Quite simply, people will tend to trust those workers who are seen to be independent of the very organisation they have difficulty dealing with, or wish to change in some way, if that is one of the problems.

# Support for projects

I would argue very strongly however that to have a project outside the structure of the service is no argument for that authority not to support the project directly or indirectly. In other words, there is a strong case for authorities to view community development in health as something they should support but which should be outside, and seen to be outside their own immediate control. Their role ought to be one of encouragement to the voluntary agency which initiates the scheme, of being receptive to the lessons that the scheme can demonstrate, of coping positively with ideas and recommendations, and of being willing to listen to the criticism of its services that may be made. There are plenty of financial and managerial devices available to authorities which will enable them to ensure that they may make. This may be a regular report, an input to a managerial body, a formal evaluation, or whatever.

### Conclusion

In conclusion, therefore, I hope that my reasons for pressing my own authority, and other bodies, to actively support CHIs, are clearer. You will note no doubt that I have spent more time on the first of these, concerned with the need for us to get close to those people whom we serve, and to learn from them and to ensure that we change as a result. This emphasis is deliberate since I believe it to be one of the principal and over-riding philosophies that we should be following in the health service today if we are together going to get nearer achieving health for



# A COMMUNITY DEVELOPMENT APPROACH TO RACE AND HEALTH Shaama Saggar-Malik

The first point I want to make is that there is no one word that embraces all members of minority racial groups in this country. The word increasingly used by people of Afro-Caribbean and Asian origin is BLACK. For the black people who have adopted it, it is a term which underlines a unity of experience of discrimination and exploitation (both in Britain and abroad) among many people whose skin colour is not white.

At the same time there are many people from ethnic minority communities in Britain who do not identify themselves as black but who, because of ethnic origin, language, cultural or religious differences, share a common experience of discrimination and inequality.

Whilst recognising that no simple term is completely acceptable to everyone, I hope to make it clear by using both terms that I include any individual who suffers the effects of racism in whatever shape or form.

My purpose today is to challenge not only some ideas you might have, but also the kinds of initiatives you may have been involved in with the black community, and the kinds of actions you may take in the future. I am here to try to say what I perceive both as a member of a black community and also as a person who is involved professionally in the health care needs of the black and ethnic minority communities. Furthermore, I am here to share some of the perceptions and some of the feelings that they are unable to put forward because they literally do not have the platform that I have today.

It is interesting to note listening to the previous speakers that only one mention was made of the black and ethnic minority communities with differing needs. I think this is an important point, because so often we talk as if the community is homogeneous. Yet within the black community there are different needs according to different ethnic minority groups, but also needs which overlap with the white community, eg people with disabilities. Consider the example of black women with disabilities. Should they be funded from money set aside for the disabled, for women, or for the black and ethnic minority community?

Before examining the issues in detail, I should like to demonstrate visually how the black and ethnic minority communities perceive the response to their health needs, both from the NHS and from the voluntary sector. (A sealed envelope was passed among the panel (excluding the speaker) and when opened by the last member, contained a one US dollar bill and a note which read: 'this procedure is more popularly referred to as passing the buck'.)

That may have been amusing, but it has a very serious point to make, because that is how your responses are all too often perceived by the black community, that we're just passed on. Nobody here challenged me as to what was in that envelope. Nobody said, 'I wonder what's in it?' That is precisely what happens in practice - 'it's not my little bit, so let's pass it on.' Very few have had the courage to say, 'now just a minute, should it stop here?' or 'am I actually passing it to the right person?'

As a result of that perception, you should consider whether we are just an afterthought, a last minute thought, or are we there right from the beginning in somebody's consciousness? This paper is a case in point. It was not available in advance because we were approached at the last minute. I notice that there are very few black faces in the audience.

Where are the black decision-Three of them work in the community. Who holds the power and who actually makes the decisions are makers? If as funders and policy makers you are unclear of the issues, and do not have black people with you to help you make decisions, then is it any wonder that the needs of the black and ethnic minority communities remain marginalised? Over the last six weeks I have met six groups who are struggling in isolation with limited funds to run entire projects to do Yet when I approach funding agencies, they in turn say 'we with health. didn't know they were there'. You as funders are saying 'we've got the money, we want to do something, but where are they?' and they're saying, 'look, we're doing something, but nobody's supporting us'. But who should be taking the initiative on funding? I firmly believe that responsibility lies with the funding agencies.

# Some issues in providing effective services to black and ethnic minority communities

Peter Jay (Chairman of the National Council for Voluntary Organisations) says in a report to the Royal College of Physicians:

'The traditional mystification of medicine, the overriding emphasis of the NHS on cure rather than prevention, the problems of gaining access to statutory health services and the reluctance of many people in the medical profession to recognise the ability of individuals to determine and articulate their own health needs has been an important stimulus to informal approaches to community health.'

While that holds true for any kind of community health initiative, the last two factors (access, and the reluctance of people in the medical profession to recognise that we can articulate our own needs and that we do know what they are) are particularly relevant to the black community. We suffer from racism, disadvantage and discrimination, all of which ultimately and inevitably have an effect on our mental and physical health. That the black and ethnic minorities communities should develop community based responses to these health needs requires no further justification, particularly as the same processes of discrimination operate in the Health Service's response to our needs.

So what are the issues that funders and other resource providers need to consider when supporting community health initiatives in the black and ethnic minority communities? I should like to point out that much of what will be said applies to other disadvantaged sections of the community, but this does not in any way lessen the disadvantage and oppression that the black community suffers, and to which you must respond. Let's look at where these challenges lie, recognising that these observations apply to other disadvantaged sections of the community as well as the black and ethnic minority communities.

The four main issues are identifying the community's health needs; responses to these needs; constraints and difficulties experienced in developing black and ethnic minority community health initiatives; and why it's important to support these initiatives.

# Identifying the community's health needs

Both the National Council for Voluntary Organisations report and the <u>Black Report</u> support the fact that black and ethnic minorities have differing health needs and that they suffer from socio-economic disadvantage and the effects of racism. All of us use the <u>Black Report</u> as ammunition when seeking to improve services. Yet in the whole report there is half a page which is concerned with racial inequalities in health. One telling comment in the report is that more research is needed to identify the expressed health needs of the black and ethnic minority communities. But what is stopping funders and researchers seeking their views in the best tradition of consumer research? Whatever approach is adopted there are questions needing clarification before any findings can be considered valid.

One, who identifies the needs? Is it the black community itself, because Very often our health needs are defined for us and in it isn't always. isolation from us. Two, what needs? When we look at the range of needs identified for work within the community, it's very limited and usually at one end of the life cycle - birth. What happens to those at different stages? What about the elderly and their future needs? Generally, most needs are identified in terms of trends in health education and promotion either particular concerns of the patron group (birth) or current fashions (problem-drinking, heart disease). But how often do we actually consider why particular needs have been identified? Is it because suddenly there's a sum of money available from government sources or from a trust fund for specific developments? Is it because funders genuinely feel that a sector of the community is getting a raw deal? Is it because the community is standing up and saying, 'listen, we have to have something done for us, this is our real need?' Or is it because the area identified is a problem for the health worker? Funders have to look at this and examine their motives for funding. They must also be honest about it. examine their motives for funding. Third, we need to examine the problems for a community trying to identify its own needs. When you're ill, you may know what makes you feel ill. However, to actually say 'why do I get ill?' is something slightly different, particularly when you belong to a community that is oppressed. To state and accept that 'it's because of the conditions I live in' can be very painful - it may actually exacerbate the situation. Denying the real causes is, for many people, a coping mechanism.

Finally, what kinds of evidence of need are required by funders of the black and ethnic minority communities? Much of what I will say applies to all community health initiatives regardless of ethnic origin. One can debate whether the classic epidemiological approaches to identifying health needs are adequate, but even these approaches are not often used with the black and ethnic minority communities. 'Special' surveys are questionable because as often as not they tend to marginalise the issue. Thus the black and ethnic minority communities are caught in a 'Catch 22'. Research is not undertaken unless there is an indication that the need is there, and yet without research how can the need be proven?

There is also another dilemma. Often the methods and concerns of research invalidate people's personal experiences, particularly the effect on their lives of external forces such as racial harrassment and poor environmental conditions. The most common manner in which black people's experience is invalidated is by using the notion of cultural reductionism. For example - 'black women suffer isolation and depression because their culture forbids them to leave their homes'. Naive analyses

such as this create negative stereotypes and images, do not inspire confidence in service providers, and clearly do not assist the design of appropriate and effective services.

# Responses to the needs

In looking at responses, three major questions need to be considered: who responds to the needs, why they respond and how? Here is a checklist for considering a response to a funding application.

- What health concerns are particularly in favour? Who decides what are the priority areas?

Once a specific health need has been identified as possibly worth funding:

- What is the response from the black and ethnic minority communities, from health workers, from the white community, from funders? Do they support it and are they agreed it is a priority?
- Is this a 'special' need? That is, is the area of need a long term or short term area of need? Could it ever be integrated into a mainstream service, or will it always remain on the periphery?
- Is this a 'special' group? That is what criteria, if any, are used to single out a group in need? Why is it necessary to consider them as a separate group?
- If there is a white group, does it include people from black and ethnic minority communities? Does it make an effort to include them? What kind of effort?

This last question is a crucial one in view of what has been said earlier about the isolation and identification of health needs. Consultation is also a vital issue. Often the so-called 'ethnic expert' is brought in. It is a dilemma I am often in myself. Invariably, my role is to put forward the 'community's' viewpoint, needs and perceptions: endless variations on the theme of 'tell us what the community thinks'. I am not the black and ethnic minority communities. I am part of those communities, one individual only.

Alternatively, you may consult mainly with 'community leaders'. From sheer desperation (perhaps because you don't know where else to go) you go to the temple priest, the church priest, usually the male hierarchy within the community. However, when you consult with the white community, do you go to your policeman, doctor and priest only? Yet, I am sure some of you do exactly that in your work with black and ethnic minority communities. Why should 'traditional' leaders in these communities be any more representative of their communities than their white counterparts? The social structures and lifestyles of black and ethnic minority communities settled in this country are as far removed from village India or a Jamaican parish as they can be. 'Traditional' community support structures, networks, consultation processes and protocol have been destroyed, disrupted or rendered ineffective in the process of migration and settlement.

The fundamental problem is that there are too few people from the black and ethnic minoriity communities in the corridors of power where the issues are identified, options selected and final decisions made. White agencies come to us for information and advice, but at the end of the day we do not have an equal say in decision making. We knock at the door, but are rarely admitted past the hallway.

# The constraints and difficulties experienced in developing black and ethnic minority community health initiatives

The biggest issue affecting the black community in the funding of community health initiatives is the principle that the work should be nonpolitical. What has not been mentioned this morning is the political nature of health and yet, when you consider funding minorities (particularly women and the black community) you cannot avoid the politics of health. To say you can only give money to projects that are apolitical and that do not challenge current health politics, is to deny the social and economic relations which affect both people's health and the services they receive. Insofar as most black health initiatives are tackling these very same issues at a community level, the political reality of their work simply cannot be ignored. A second issue when we talk about black community initiatives is to do with the definition and size of the 'community'. Often a community with its own range of needs can be spread throughout a borough or small town and yet those on one side of town are expected to travel long distances to attend special provision or community facilities. conveniently overlooked is that the black community on one side of town is not always the black community that's on the other. Policy makers need to know their black and ethnic minority communities better and should ensure that initiatives are accessible and take into account differing needs and demands within those communities.

Finally, even once projects have received money, the problems don't stop there. Projects which are established with a limited brief (for example to provide advice and information to their community) often find themselves loaded with total responsibility for that community - without additional funding. Inevitably they become overloaded. Persistent overloading means they eventually become inefficient. What happens when they become inefficient? They no longer fulfil the criteria for which they were funded. Chop goes the grant. The advice and information project referred to found itself organising a lunch club, a bereavement counselling service and other facilities for the elderly without extra workers or funding. When the time came for an extension of their grant they were told 'you're not doing what you were set up to do so we can't refund you'.

# Why it's important to support these initiatives

Community health initiatives can be divided into two broad categories: those which deal with people's rights to a free, comprehensive and sensitive service and those which help groups to articulate their needs and develop alternative approaches to meeting them. Most black and ethnic minority communities confronted with a racist, unresponsive health service are still running to keep still, plugging the gaps, maintaining minimum rights for their communities. Black groups need the opportunity to develop their own strategies and solutions and they need to be given that opportunity by funders who understand their needs.

I will end with a quote from Samuel Taylor Coleridge, composer and black activist, who said in 1912:

'There is, of course, a large section of the British people who are interested in the coloured races, but it is, generally speaking, a commercial interest only. Some of these may possibly be interested in the aims and desires of the coloured peoples, but, taking them as a whole, I fancy one accomplished fact carries far more weight than a thousand aims and desires.'

In conclusion I would ask you to actively support the black and ethnic minority communities in proportion to their real needs. It's what you  $\underline{\text{do}}$  that counts.

# EVALUATING COMMUNITY HEALTH INITIATIVES: AN OVERVIEW Alan Beattie

At first glance, the idea of evaluating community health initiatives seems such a good one: an eminently simple and attractive proposition, self-evidently a good thing, and merely requiring time, resources, and technical expertise in order to be accomplished. But, in this paper, I want to suggest that on the contrary evaluation in this field is complex and difficult, and can be threatening and challenging; and calls for the most careful deliberation and consultation among those contemplating such an activity. Even so, I want to argue that evaluation is essential, and it should be built into every community health initiative, and that attention to evaluation should be a key concern of every practitioner. I shall use this paper to argue this case, and to review some of the directions in which evaluation studies can be developed and the issues which they must confront.

I will be summarizing, and at times I fear I may be oversimplifying, a large, rapidly expanding and fascinating area of work. Just as recent developments in health policy have been dominated by the opening up of vigorous and turbulent debates concerning alternative strategies for health promotion and for education<sup>1</sup>, so also in the evaluation of policy and practice, there are currently profound disagreements about what evaluation is, who should do it, how it may best be conducted, and so on. My own interests and involvements span health services, the education system, and community work; and it constantly strikes me (and frequently bemuses me) that there are tantalizingly close parallels in the issues surrounding evaluation in those different fields; accompanied by what seems at times like total mutual incomprehension.

But even within each of these fields, there is dissension concerning the distinctively different approaches to evaluation that have emerged. Sometimes different approaches are seen merely as technical alternatives; more often they become the focus for mutual suspicion, prompting accusations of sloppiness and counter-accusations of over-precision; and at other levels, alternative strategies of evaluation are regarded as bound up with profound political and/or ideological positions. At the very least, we have available nowadays both traditional or 'classical' canons of evaluation methodology, and 'new wave' ('non-classical') techniques, and the merits and demerits of these need careful consideration. I hope that my paper will offer a map of this terrain, and may open up a dialogue between practitioners from different backgrounds.

I would like first to outline four broadly different strategies in evaluation studies, and I shall try to illustrate these wherever possible by examples from community health programmes.

### Measuring outcomes

In the health field, perhaps the most widely canvassed approach to evaluation is that which seeks to apply the sophisticated research techniques of modern epidemiology. Controlled field trials of a particular intervention are set up (ideally) to ascertain the outcome in a group of people who receive this intervention, by comparison with groups who do not 2. This approach is best known as a basis for regulating the introduction of new drugs and other therapeutic and preventative techniques 3 and has been advocated as the foundation for rational health care - whereby the allocation of resources would not be controlled by pressure groups but be informed by analysis of benefits and costs 4.

A review of evaluation studies in health education showed that while many attempt, few succeed in satisfying the statistical and technical rigours of research design that this approach demands. Nevertheless, two recent community-oriented programmes of coronary prevention employed this evaluation strategy (and have thereby been enabled to demonstrate successful outcomes).

Apart from the intellectual intricacies and pitfalls of research design in this approach, other difficulties arise. It is difficult to apply in situations where control samples are not available or are not ethically possible; and though there are ways round this , there then arise difficulties of statistical inference? A more fundamental difficulty is that in many community health programmes the significant population variables which the research design would need to take into account are simply not known; and moreover that any measurable health outcome, such as indices of mortality or morbidity, may be far-removed in time, taking perhaps several years to show up  $^{10}$ . And finally, for many community programmes, there may be no single and simple 'outcome' measure that can be used as an evaluation criterion  $^{11}$ .

### Monitoring processes

In the health field to some extent, especially in community health education, but most clearly in consumer-related fields (audience research, market research) there is a relatively simple and long-established approach to evaluation in terms of 'exposure' or 'penetration'. The strategy here is typically to use survey techniques to enumerate attendance at a particular event, or uptake (purchase, sales, etc.) of a particular service or commodity 12. Even basic head-counting has its own statistical disciplines of course, and problems of sampling methodology need to be considered 13. Further sophistication may be brought in by 'before and after' survey designs, which lead on to time series sampling, trend analysis, and cohort studies 14. Another direction in which greater complexity of data may be sought is by going beyond behavioural head-counts to the monitoring of knowledge, attitudes, and self-reported behaviour, by means of questionnaires 15. Versions of this approach are widely and routinely used in the evaluation of community health programmes. For example, guidelines for evaluating parent groups have been published by the National Children's Bureau 16, which themselves draw on evaluation projects in family group work, pre-school play groups, and community education 17. Similar survey methods have provided an informative evaluation of family planning education programmes 18.

Thus, this approach offers a kind of 'social audit', that can reveal trends and distributions within populations and population groups, and when conducted on a periodic (or longitudinal) basis, and in specific localities, it can provide a crucial dimension in monitoring a particular project or programme. One well-documented example which shows this is the evaluation of the Open University Community Education Programme 'The First Years of Life' 19.

Difficulties of research design and of statistical inference are less daunting in this approach (though they cannot be ignored). On the other hand, the challenge of specifying and measuring independent 'outcome' variables is avoided, and 'monitoring processes' as an evaluation strategy is open to the criticism that it can assess only in terms of internal 'norms' of efficiency rather than external 'criteria' of effectiveness 20.

# Analysing clients' perspectives

Another approach to evaluation which has gathered momentum recently is to use qualitative and descriptive data, to elicit and/or articulate the reactions of clients to particular social interventions  $^{21}$ . This strategy would typically employ interviews, group discussions, and similar means to obtain conversational data, for subsequent analysis and interpretation  $^{22}$ . Such techniques have become especially common and familiar in educational research  $^{23}$ , in particular in curriculum evaluation, both in schools  $^{24}$  and in higher education  $^{25}$ . They have been brought to prominence in the health field most especially in connection with studies of women's experience of health care and health education  $^{26}$ .

What this approach frequently reveals is the discrepancy and dissonance between the assumptions of the practitioner and those of the client; and rather as in the immediacies of client casework<sup>27</sup> so also in the longer time-scale of programme planning<sup>28</sup>, the most important feature of the approach may be that it permits a renegotiation and reorientation of an intervention, to 'bridge the gap' between client and practitioner perspectives. Thus this kind of evaluation can be 'formative', using feedback to help shape a programme as it proceeds, rather than 'summative', waiting until 'after the event'.

Any notion that simply talking to clients offers a spontaneous and direct route to the authentic evaluation of a programme needs to be strongly resisted, however. Skills and discipline are demanded by this approach also, in order to give focus, structure, and coherence to the conversational data; and several different academic schools of thought compete for the attention of the evaluator who embarks on such work, ranging from 'personal construct' psychology<sup>29</sup> via ethnomethodology<sup>30</sup> to sociolinguistics<sup>31</sup> - to mention but a few.

For those more familiar with the classical canons of the 'hard sciences', this approach appears to give a licence to subjectivity and to the free play of 'inference' and interpretation. A legitimate rejoinder to this is that in social and educational research, exploratory techniques that can map individual and group differences with the fullest sensitivity are essential to offer insight into unforeseen and unpredictable responses; and that these problems of inference and interpretation are best resolved through 'checking of accounts' with the informants whose reactions are under scrutiny 32, so that (ideally) researcher and informant together 'reflect' upon the problem of representing the client's views.

Two broad findings that emerge from studies of this kind in health education are noteworthy. One is that clients' reasonings about health matters, and the factors that determine health decisions, are often more complex and varied than is assumed by many health education programmes 33. The second finding comes from current work in my own Department by Wendy Farrant and Jill Russell, who from a series of case studies of particular health education materials have been led to suggest that "professional health educators tend to underestimate the amount of appropriate health information that 'ordinary' people want" 34, and that (for example) much fuller explanations of 'alternatives' and of 'risks' in health choices need to be provided by health education programmes.

Several features of this approach seem likely to recommend this approach to those contemplating the evaluation of community health initiatives. Firstly, it can yield illuminating information that can directly guide practice; and secondly, it can be incorporated into the work of the practitioner, on an ongoing, 'formative' basis. Thirdly (and I suspect most

tellingly) it reflects a concern to 'give a voice' to client groups whose interests it is a particular ambition of community development strategies to champion. If this is so, it gives particular urgency to the need for clarification of the skills and difficulties of this approach, and for a systematic comparison with other approaches.

# Appraising institutional agendas

The recent growth of 'non-classical' qualitative evaluation has been somewhat dominated by a concern to articulate the perspectives of the clients, which may be regarded as no bad thing by many of those involved in community development initiatives in health. But it has overshadowed an alternative form or facet of 'non-classical' evaluation research which in some respects has an even longer pedigree. This is an approach to evaluation which is similarly open-ended, but which seeks to identify and map as widely as possible the 'context' - social, cultural, political - within which a particular programme is conducted, and which attempts to portray as accurately as possible the displacement effects, the 'impact' of a programme. This impact may concern the debates and conflicts to which a programme contributes in a particular agency or in particular professional groups; it may concern the discrepancy between a particular programme and wider prevailing climates (as seen in other parallel and contemporary legislation, taxation, resource allocation policies). approach has its foundations in policy studies and political sciences, and draws upon the disciplines of social history 35 and cultural anthropology 36. An evaluation of this sort will typically undertake a systematic scrutiny of official documents, prospectuses, agenda papers, minutes, memoranda, letters, and/or a programme of observation and recording of official meetings, formal interviews and informal conversations with key personnel, backed up as appropriate (and where possible) by analysis of 'curriculum vitae' data on these same key staff. Such evaluation research is likely to be in the form of case study, or comparative case studies, and can result in a 'portrayal' of the 'natural history' of a particular intervention programme: how it runs its course; what kind of broader and longer-term interests are brought into play and put at stake; what influences support it, and what obstruct it; what ideas about what counts as 'success' or 'failure' in a health programme are in circulation, and which dominate. Given the limited deployment of rational health planning techniques to date, as noted earlier<sup>37</sup>, it is in fact curious how little research is directed to the systematic appraisal of policy-making processes and of the ways in which priorities and programmes do emerge from the interplay of conflicting interest groups and long-term institutional frameworks.

A study of a community-based family planning project in Latin America illustrates the insights available from such an approach <sup>38</sup>; and the Health Education Publications Project in my own Department has also been able to open up this dimension of evaluation, in one case study, as a result of a remarkable degree of cooperation by the Health Education Council, in making its own policy-making procedures available for investigation <sup>39</sup>. This study also illustrates an important parallel in this approach with that which sets out to analyze clients' perspectives, which is that one of the most significant features of such evaluation research may be to negotiate a 'contract' with the client or agency under scrutiny, in order to gain information, but also in order to 'check accounts' with the informants and to use the information to shape the programme itself. The best developed and most sophisticated versions of this approach to evaluation are perhaps to be seen in projects which have begun to explore the 'self-evaluating' institution, in the education field <sup>40</sup>.

## Towards a conclusion

I hope I have shown that each of the four approaches to evaluation that I have described has its own inner logic, coherence, and discipline. These distinctive inner logics in themselves partly bring about the conflicts and confusions in this whole area of work. 'Measuring outcomes' and 'monitoring processes' both relate most closely to the intellectual disciplines of 'low inference', objective, quantitative (in a word 'positivist') research familiar in the physical sciences; whereas 'analyzing clients' perspectives' and 'appraising institutional agendas' relate to the different intellectual disciplines of 'high inference', interpretative, qualitative research, familiar in the social sciences and the humanities. different axis, 'monitoring processes' and 'analyzing clients' perspectives' both have the merits and demerits of looking within a programme in order to evaluate it; whereas 'measuring outcomes' and 'appraising institutional agendas', share a concern to evaluate by looking outwards, beyond the programme itself and its clients, to wider or longer-term issues. perhaps not surprising that there is confusion and conflict about evaluation....

I would like to conclude by suggesting that there are several different strategies that can be adopted in the face of these alternative approaches to evaluation. I have given them titles as identifiers, and I apologise for further raising the jargon quotient in this field.

# Pragmatic eclecticism

A sensible and modest position may be to start evaluation 'where you can', where you have a point of access. It may be that someone, somewhere has resources in the way of data bases, computers and statisticians which make it unreasonable not to try to 'measure outcomes'. On the other hand, the resources (even of time) may be so slim that 'low technology' evaluation methods, based on participant/practitioner research, using conversational data, may be all that is feasible. Whatever the starting point, opportunities to move into other <u>dimensions</u> of evaluation should be sought, and the limitations of any 'unidimensional' study should be carefully attended to.

# Principled heurism

Wherever possible, however, I would argue that a 'multifacetted portfolio' of evaluation research studies should be encouraged, by project workers, by funding bodies, and by academic consultants, advisors, etc. This would acknowledge that evaluation is a complex, elusive business, akin perhaps to a 'detective story', that requires all clues to be followed up that may lead to understanding and resolution of a particular case in point. Just as in the physical and biomedical sciences, it may be that we have to accept that evaluation of community health initiatives will increasingly in the future require large 'multicentre' teams of researchers, something like 'big

# Academic scepticism

I am also bound to say that in a field so intimately connected to issues of power and control, issues of knowledge and authority, issues of social justice and individual need, no evaluation project, however careful, comprehensive, and sophisticated its design, will be free from turbulence and dissension. I have to say that I believe there is merit in a position of academic freedom of inquiry and dispassionate curiosity, so that in dark moments when confusion reigns and every claim to truth and trust is matched by a counter-claim, I can remind myself that, of course, we need an anthropology (or is it a political science) of research itself as an activity within the bureaucratic agency and professional subcultures of modern society.

# EVALUATION IN PRACTICE Diane Plamping

Let me begin by explaining that my professional responsibility is to promote dental health. One part of my strategy for achieving this is to be involved in health education. I have sought ways of working which are consistent with my beliefs in the social causes of ill-health and in the limits of medicine but which allow me to use my professional skills. This search can be dispiriting. One can find support for the ideas from the writings of the 'great and the good'. There is much less written on what one can do, particularly if one's interest is in small scale community projects rather than in national policy. Generally one feels that these policy statements say 'if I wanted to get there I wouldn't start from here'. But here is exactly where we start in community health work.

I hope my experience will provide one example of what can be done and how a project can be evaluated. This is not intended to provide a blueprint, rather to show how any evaluation must be tailored to the needs of the particular project. I will describe one project, the broad aim of which was to improve the effectiveness of health education through the use of peer teaching. Initially, my idea was children teaching children would overcome the usual barriers between health professionals and lay people who differ from each other with respect to class, race, age, gender, use of language, experience and expectations. It was assumed that the knowledge people need is understandable and can also communicated by most people, including children, and that such knowledge is necessary, if not sufficient, to make health choices easier. The project began in 1977 with children in a health club in West Lambeth's Community Health Council (CHC) premises. The assistant secretary had organised the club events in response to two of the children calling at the CHC's shop and asking to help. When I became involved the children agreed to work with me to learn how to teach other children about dental health. During this work with the children I became aware that the objectives with which I was working were inadequate. They did not relate to the wide ranging experiences of the children and myself and the people we contacted in our So, in 1979, the objectives were reformulated and a method of evaluation evolved which was designed to:

- 1 Enable the project workers to clarify their aims and understand the processes involved in their work;
- 2 Reflect an educational activity in which aims and objectives change;
- Make the experience of this educational activity available to other people, including non-specialists;
- 4 Create a framework to allow comparison with other educational programmes.

The evaluation was based on the identification and analysis of key themes and incidents in the children's experience of the education practice.

Four themes were identified:

health as a pleasurable experience; perceptions of health; competence and responsibility; social networks.

Our practice was influenced by our recognition of several current debates:

The limits of medicine; Social and political determinants of sickness and health; Communication problems between practitioners and their patients; The problems which may arise in hierarchical organisations.

concentrated on health education, including promotion; some We understanding of the causation of health and sickness; and on the development of the children's confidence by encouraging them to take responsibility for their own learning; and teaching within a non-hierarchical setting where professionals were treated as a resource who had something to learn as well as something to contribute. Like many others, we believed that peer teaching was a good thing but we wanted to understand how it worked. We were able to articulate the questions that our work, so far, had raised. We developed them through discussions with the steering group and the full CHC. The steering group was made up of workers, CHC members, children and external advisors. The questions included: What areas should be stressed? Are we looking at behaviour change? How do we define our terms? What is health education? What do we mean by peer? What do we mean by competence, benefit, improvement? Can we define beneficial? What is improved behaviour, is it just conforming, in which case does it benefit the teacher or the child?

Rather than concentrating on behaviour change we tried to encourage the club members' self-confidence (an important part of health) through their experiences in the club, not only of teaching, but also having some control over the content of the health education they give and receive. Our coverage of health topics included nutrition, smoking, dental care, foetal development, pollution, handicap and health care in other countries. We were influenced in our philosophical stance by the work of people like Holt<sup>41</sup>, Kohl<sup>42</sup>, Daniels and McGuire<sup>43</sup> whose work gives examples of the eagerness with which children grasp relevant opportunities to learn. We always attempted to make our objectives explicit and to review and modify what we were doing. In addition we set out to explore an approach to evaluation because we felt it was vital to develop a framework for discussion with people outside the project.

We began to explore the children's feelings about the club, their perceptions of health, their feelings of competence and responsibility in relation to the club and their teaching, and their networks of contacts with other children and adults outside the club. We did this by collecting and analysing critical incidents. In this technique the critical incident is a snapshot, or a slightly focussed description of a significant event which throws light on a subject or issue under observation. Another feature of our method was participant observation. This is observation by a person actively involved in the activities. Its origins lie in anthropology. Anthropologists immerse themselves in the day to day life of a village, for example, in order that their presence does not distort or influence the social processes. The participant observation was carried out by Lesley Levane, the full-time worker, during the course of her work with the members, visitors and teachers. These observations were recorded in a diary. The analysis of this information was conducted by the evaluation

group. For this analysis a framework was devised which identified the four themes of the children's health education experience. These themes were used to formulate trigger questions which were used for interviews with the children. We were able to use these themes as a framework for analysing the documentation gathered during the year. Lesley tape recorded the interviews with the eleven most regular attenders, seven individually and two groups of two. The evaluation group then listened to the tapes and recorded, for each theme, relevant comments made by the children which were then discussed. Lesley collated the information which then came back for further discussion.

An example of a critical incident taken from the worker's chronicle on the theme of competence and responsibility is the time Darren and Dave (aged 12 and 11) taught 15 year olds about foetal development. The older children were impressed. 'How old are you to know so much?' asked one pupil. 'Old enough', replied Darren. They were very proud of themselves for teaching people older than themselves, but this was not an experience they wished to repeat and insisted in future that all their pupils should be nine years or younger.

Other club members, having learned of Darren and Dave's experience of teaching adolescents began to ask the age of children they would be teaching and set an upper limit one or two years younger than themselves. This seemed to relate to the children's perception of themselves as teachers and the need, particularly in the early stages of teaching, to command respect.

Trigger questions on this subject also suggested that the understanding of the difficulties of teaching is complemented by a desire to understand other work and ways in which this can be achieved. When asked 'who would like to come and talk to the club' (question 51) Sarah said she felt like this about the chemist who came 'I thought he was very stern and he didn't let the children ask questions......he just went on and on about medicines.'

To be honest, the original incentive to evaluate the project came from the need to gain funding to pay the full-time worker for the project. In the proposal submitted to the King's Fund we suggested in fairly non-specific terms that we would evaluate the project's effect. The Fund gave us a grant which was sufficient to employ a worker who had adequate time to undertake the proposed evaluation. We were also fortunate, using our own networks, to be able to find people with the appropriate technical skills and a commitment to community health development to join our evaluation group. Although what I will do now, is catalogue the problems we encountered, let me say at the outset that I am really glad we did it. I now see it as a huge bonus rather than a burden. It is interesting to speculate why we should ever consider evaluation a burden when most of us are fairly reflective and systematic in the review of our every day activities. I suggest that most of our experience of formal evaluation or assessment of it is being done to us rather than by or for us. Hence we are often left wondering

why evaluate? in what context? by and for whom?

Added to this is our awareness that the call for the evaluation of CHIs does not always come from disinterested parties, whose only interest is in pushing forward the frontiers of human knowledge! These calls are often wielded like the blunt instruments implicated in cases of murder. How are we to react to these calls for us to produce the facts and the evidence of our effectiveness? So what facts are needed for an evaluation of a community health initiative?

Indeed what are facts? This question may seem an unnecessary diversion into the philosophy of science but I think it is central to the confusions we are addressing today. Rooted in everyday observation, built into contemporary common sense, confirmed by statistical procedures, facts are used to prove accepted theories. This becomes a problem when there are opposing theories such as the medical versus the social model of health or individual versus social responsibility for health. Facts have evaluation implications and are wielded as reasons for or against a particular view. The business of establishing facts and their degree of reliability is not a value free activity.

For those of us in community health projects who are facing a prevailing orthodoxy - such as the medical model of health - I would suggest the following strategy. We should produce new facts and we should reintegrate both new and old facts into their social contexts or evaluative relations. While the study of things separated from their contexts has proved useful in explaining how things happen and produce findings which have predictive power, they rarely describe why things happen or have explanatory power. We should accept that most scientific knowledge is established by a priori forms of argument and that data illustrates theories rather than tests their truth or falsity.

The lack of scientific evidence to support the effectivenes of most common medical practices is insufficient reason for us to practice the same illogicality. And even if it were, it would not be expedient, politically, given the balance of power. For in community health work like health education current practice is, to a large extent, being carried out under conditions dictated and ground rules laid down by medicine. Some effort must be made to confront this problem, without conforming to the biassed objectives and the unilateral working methods imposed by the medical model.

I too am committed to scientific evaluation based on systematic observation and ordering of data in a given context. One part of this process is the specification of one's objectives and here we hit another problem. What are legitimate objectives and are we brave enough to state them if they challenge the status quo? Furthermore, would you fund work based on these objectives? Initially specifying objectives can seem like an imposition on top of a full plan of action. Eventually we saw it as having been instrumental in enabling us to carry out the programme. The recognition that we could describe our theory and that we could generate hypotheses from it gave us self confidence and made us value the work differently as well as increasing our understanding of what we were trying to do. It is surprising how one tends not to value one's ideas or the initial imagery one brings to a concept like health promotion. I was equally surprised how good it felt once these views were made explicit and available to other people. Finally we identified what we called themes (above), which we thought would illustrate the nature of our work.

These themes were a sort of half way house between process parameters and research objectives and may be seen as unusual in their form and content. We felt that they related to the process in which we were involved and through articulating them we grew more confident of their appropriateness. With discussion among all the participants, including the children, and further reading we felt better able to defend them. I am sure you know that your concept of health is rich and has many facets or dimensions even if their empirical meaning is not immediately clear. Developing this confidence takes time, and time means money. Funding agencies must be willing to pay for realistic efforts to evaluate projects.

How to appraise our work with respect to these themes became the next problem. To take our first theme, how can one measure having a good time? We do this, of course, every day of our lives but somehow that doesn't seem to count as evaluation. It is quite difficult to hold on to one's belief that quantity is only one aspect of expressing quality. Rejecting quantitative and experimental methods for evaluating this project was difficult in spite of my firm belief that they were inappropriate in this study, where a consensus on aims or methods of analysis could not be assumed, where there were no known cause and effect mechanisms and where quantification was not feasible. These difficulties may arise from a peculiar ethnocentricity, produced by my training, but I would be surprised if many of you did not recognise the unease I felt.

I am pleased, however, to report that the selection of non-quantitative indicators was relatively painless. There are a wide range of qualitative techniques, some breathtaking in their ingenuity and elegance. Some involve only slightly less jargon than my own specialty. Historical, anthropological and ethnomethodographical approaches can all provide indicators that produce data within context and insights and explanations within a specific context.

Just as an alternative learning strategy, peer teaching, had been adopted to achieve unorthodox educational aims, so alternative methods were needed to evaluate them. In both cases one has to learn how to facilitate rather than dictate which requires everybody getting involved. In our case that included the children as well as workers and specialist advisors in the evaluation. We chose focussed interviews and diary writing as our major research tools. We were concerned to assess the validity of our findings but we felt that the criteria of validity of interpretive knowledge were different from those for experimental data. We assessed our findings by data collected from different participants relating to a common experience. The tape transcripts, containing the raw data, were examined by several people. In this way we believe we produced data which was valid as empirical observation and as an expression of social meaning.

As with other methods, bias may be produced when interviewing. As Piaget said,

'It is hard not talk too much when questioning a child, especially for a pedagogue. It is hard not to be suggestive. And above all, it is so hard to find the middle course between systematisation due to preconceived ideas and incoherence due to the absence of any directing hypothesis.'44

It is worth pointing out here that community health research suffers from the <u>same</u> methodological limitations as other types of social research. Indeed, similar problems are found even when it is possible to use so-called objective measures.

Which problems are studied?
What is to be measured?
Which measurements are to be reported?
Is the test valid?

I have argued that social enquiry involves a logic and a particular approach to the problems of research design, measurement and analysis in which the quality of argument is as crucial as the quality of data. There are, of course, no absolute standards for assessing quality. One must consider for whom and for what purpose the evaluation is being done. And I would ask all of you to consider the criteria you apply to the evaluation of community health initiatives and whether these criteria are appropriate.

Using these methods, we were able to demonstrate that the children enjoyed their health work at the club and that the club and its peer teaching activities were an important part of their lives. They showed themselves capable of exercising some control over their own and other people's learning and could embrace a broader perspective on health than the 'prescriptive' approach most commonly associated with health education. They developed in self-confidence and had confidence in their own competence to teach and plan teaching. We learned from the children that the club was not an isolated feature of their lives but that they were able to link this health education to their own networks. We learned that these networks were local and that small numbers of people in a study was a feature of this kind of health work rather than a methodological flaw. We hope that the evaluation exercise will lead to other workers considering the implications for their own work.

For me, my involvement in this community project has been an exciting learning experience. Community health initiatives have offered me an opportunity to examine my role as a professional health worker and to find ways of being a resource rather than being responsible. Seeing the project evaluated and taken seriously by outsiders has been a powerful experience for the investigators and for the people with whom we worked. Again there are lessons to be learned from the women's movement. Women have found that it is important that our experience does not remain private if we are to share and learn from each other.

Therefore I conclude that to embrace the need for evaluation, it is not necessary to embrace all the assumptions and criteria of validity inherent in the empirical scientific approach to knowledge and measurement. Rather, I view evaluation as a systematic and accessible review of our work. However, I accept that measurement, or at least classification, is necessary. We should, however, be clear when it is appropriate to use classification, ranking, or numerical measurements. I feel our commitment to changes in health includes a commitment to evaluation. Furthermore I believe that in significant ways it can be scientific when it includes clear theorisation, a statement of objectives, and details of the techniques used in the analysis of observations.

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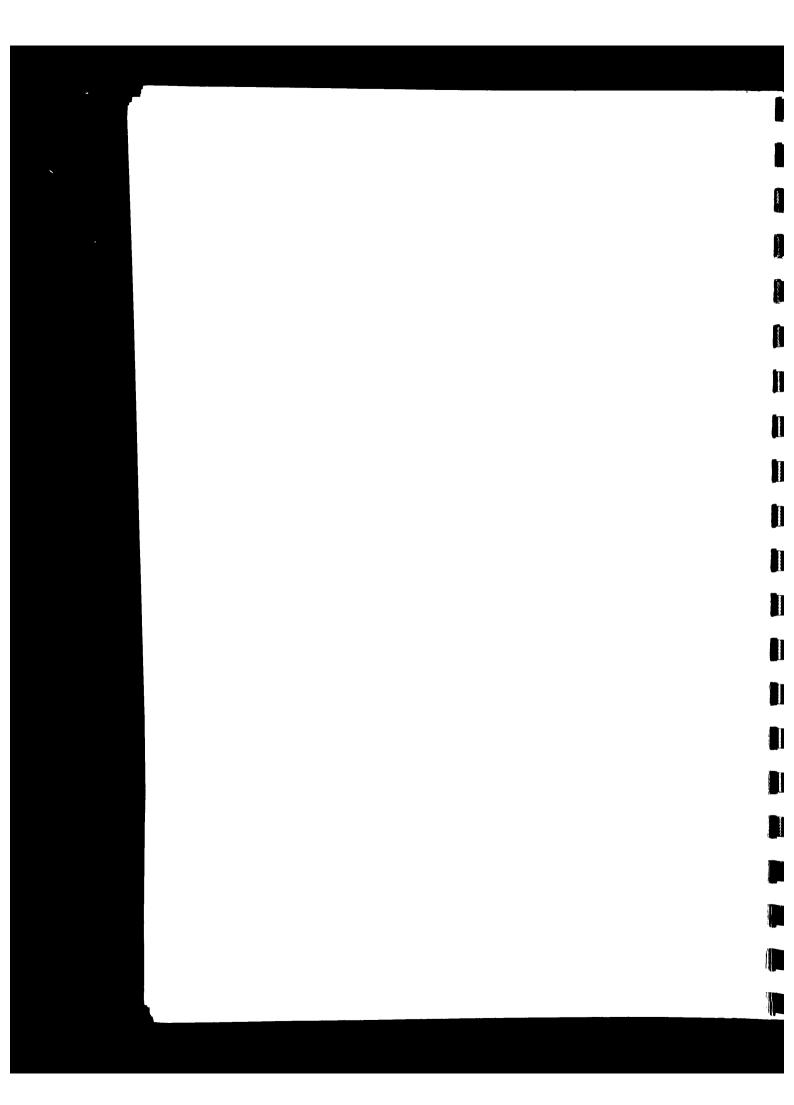
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## **CONTRIBUTORS**

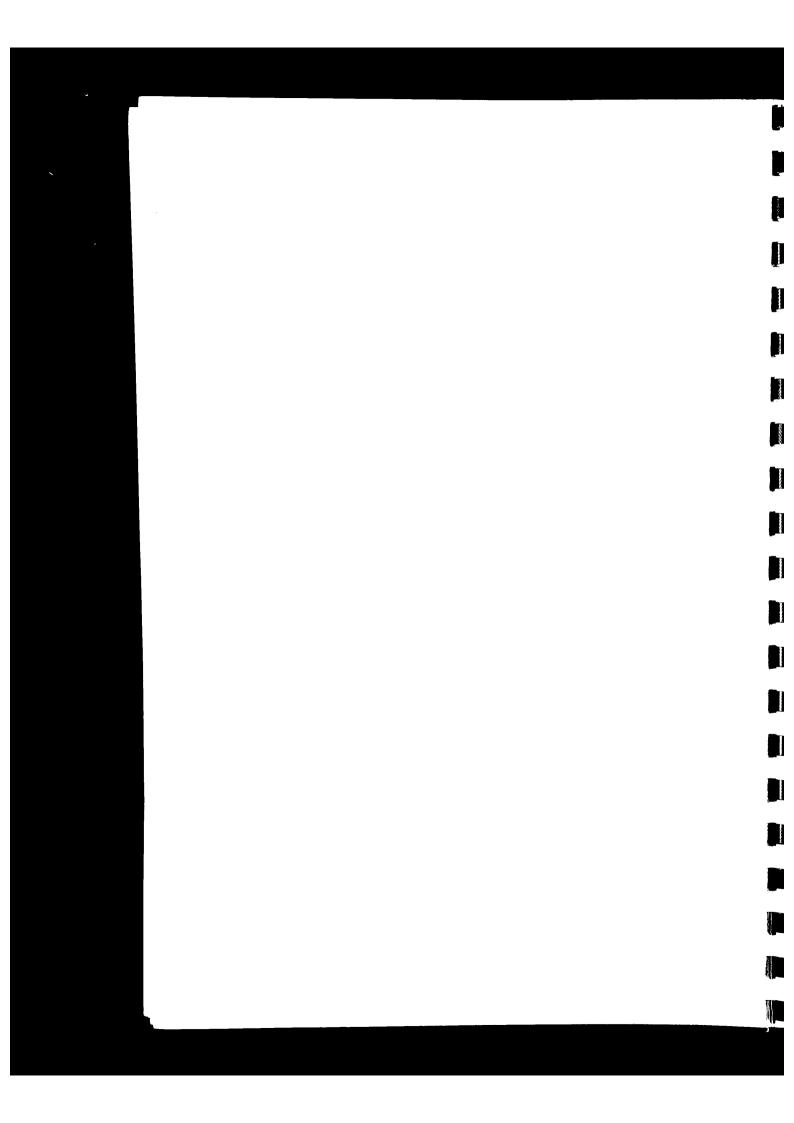
Alan Beattie is head of the Department of Health and Welfare Education at the University of London Institute of Education.

Robert Morris is District Medical Officer, West Lambeth Health Authority.

Diane Plamping is Senior Lecturer in Community Dental Health at the London Hospital Medical College. She was formerly Senior Lecturer in the Department of Community Dental Health in Camberwell Health Authority.

Shaama Saggar-Malik is Assistant Director Planning and Development in the London Borough of Camden Social Services Department. She was formerly a member of the Training in Health and Race Project Team.

Alison Watt is Lecturer in Community Health Education at the School of Applied Social Studies, University of Bradford. She was formerly Development Officer for the Community Health Initiatives Resource Unit.





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