# COMMUNITY DEVELOPMENT IN HEALTH:

## Addressing the confusions

Available from King's Fund Centre, 126 Albert Street, London NW1. 01-267 6111

Ref. KFC 85/141 – Price £3.00

Copies are also available from:

London Community Health Resource, 68 Chalton Street, London NW1 1JR. 01-388 0241

Community Health Initiatives Resource Unit, 26 Bedford Square, London WC1B 3HU. 01-636 4066

**Photographs**
Page 10a – Brenda Prince
Page 16a – Nick Oakes
Page 22a – Vicky White
Page 44a – Corry Bevington
Page 60a – Nick Oakes
Page 74a – Mike Tomlinson
Page 96a – Vicky White

# COMMUNITY DEVELOPMENT IN HEALTH:

# ADDRESSING THE CONFUSIONS

by Gwynne Somerville

Edited and produced by London Community Health Resource

Contributions from: Alison Watt
Shaama Saggar-Malik
Dr Robert Morris
Alan Beattie
Diane Plamping

Report of a conference organised by the King's Fund in collaboration with the London Community Health Resource and the Community Health Initiatives Resource Unit, held at the King's Fund Centre on 13th June 1984.

# Contents

# Preface

This conference arose out of the work that the London Community Health Resource has been doing since 1981 with health groups and workers in London who are interested in community development. By the very nature of our work, both we and the people we work with are constantly trying to clarify for ourselves what it is we do and why it is important. But now the need is becoming more pressing to present and explain our work more widely, especially to funders and influential sections of the Health Service. For the vast majority of these community health projects and initiatives have been dependent on 'soft money' from trusts, charities, quangos (eg the Health Education Council), and the local authorities and Health Authorities (usually through the Inner City Partnership and Urban Programmes). The ending of the initial period of funding of many projects after what is often no more than two or three years has unhappily coincided with severely reduced budgets and retrenchment in the NHS and local authorities. Competition for funding is acute, and those projects which present the greatest challenge to the authorities will be amongst the first to be dismissed as irrelevant, or irritating thorns in the flesh of hard pressed managers, planners and service providers. Those projects which present less of a threat and offer some kind of support or service to particular groups of people may find themselves in difficulties for different reasons. It may be tempting to see them as cheap alternatives to NHS health care provision. This they are not and cannot be.

The pressure is on therefore to demonstrate the importance of these projects and initiatives, but their limited lifespans and budgets directly affect their ability to do this. In recognition of this, and also of their contribution to the debate and to real change in the health and health care of working class people, we decided that a major conference should be held. We joined forces with the Community Health Initiatives Resource unit whose work covers the whole of Britain, and the conference was planned and organised with the help and encouragement of the King's Fund Centre. The conference would give community health projects and initiatives from all over Britain the opportunity to present their work, and to meet and discuss with the funders and Health Service personnel who will be so important to their continued existence, and to the surrounding debate.

The material for this report arose from the speeches, workshops, discussions and exhibitions which took place at the conference. The report is then a unique collection of up-to-date information about a quickly changing and threatened area of community health activity. We decided, however, not to attempt to produce a blow by blow account of the day's proceedings which might be confusing for those who did not attend the conference. But looking back over the conference material, several major themes emerged which made it easier to make sense of the very differing views and projects presented. We decided therefore to group the material from the conference using these themes as chapter headings.

We hope that this report will interest all those concerned with the provision of health services. We hope it will be used by people working with community health projects and initiatives who want to know more about the experience of others, and who are or soon will be looking for funding. The information contained in this report on a wide range of initiatives, their successes and difficulties, will also be useful to those who are not yet familiar with community health work.

The report shows that while there are not easy answers about how to do community health development work or about quantifying its value, there are none-the-less many projects applying themselves with great energy and imagination to the problems of access to health care and information for particular groups of people. We hope that service planners and providers will respond positively to a challenge presented by some of the projects.

Lastly, and most importantly, we want to show through this report that it is no good expecting community groups and community health workers to carry on doing health work which is clearly needed unless they are properly resourced and funded. Most of the projects described could not have been set up or sustained without paid workers or a budget. The community needs more than goodwill and voluntary work to take up the challenge of asserting its needs. We hope then that this report will persuade funders that these kinds of projects and initiatives are worth supporting in a generous way. For it should be remembered that many of the existing workers are paid considerably less than they would be paid if they were employed in a statutory organisation. They work in poor conditions, often in isolation and with the constant insecurity of short-term funding. How absurd this is when their aims are the long-term aims of redressing the balance in favour of those whose health and health services are the poorest, and helping those communities have an effective voice in doing that.

Helen Rosenthal
London Community Health Resource

March 1985

# Introduction

In 1979 I had the privilege of chairing (with Helen Rosenthal, from the London Community Health Resource) the first King's Fund conference on the role of community development in health (1). This earlier conference was a modest affair, involving some thirty participants, both NHS professionals and people active in neighbourhood health initiatives. It explored how community development approaches might be helpful in increasing the relevance of health services to local needs and promoting good health. At that time, there was limited experience - at least in Britain - on which to draw, although useful lessons were emerging and something of the potential for the community health movement could be identified. Five years later, the conference reported here provided the opportunity to examine how far this potential is being realised, and more importantly, to explore how what has been learnt in the intervening period could contribute to meeting the challenges to health and health care which can be anticipated in the next decade. On this occasion I shared the chairing role with Sir Douglas Black. There were well over a hundred workers and community representatives from neighbourhood health initiatives, personnel from all sections of the Health Service and officers of funding agencies. Most significantly, as this report accurately reflects, there was also a great wealth of well-developed local projects to consider.

The King's Fund itself played a small role in promoting the growth in community health initiatives, particularly in London. Some of the projects where the Fund has made a financial contribution are described in this report. These include the Bethnal Green Health Project, the Haringey Greek Cypriot Womens' Health Group, the Springfield Hospital Advice Project, the St Thomas' CHC Health Club and a study of the role of Health Visitors in a neighbourhood health project (See Chalkhill Neighbourhood Project, page 58 ). In order both to support and learn from projects of this kind, the Fund has also sponsored the London Community Health Resource which has produced this report.

Such projects have been an important stimulus in reorientating other aspects of the Fund's development activities. These include a major programme of work designed to make primary health care services more relevant to the needs of deprived inner city populations. A more specific initiative aims to promote appropriate policies on race in the NHS (2). In my own area of work, the development of community-based services for people with long-term disabilities, we are particularly concerned to ensure that clients themselves are centrally involved in shaping new patterns of services, whether for people with mental handicap, mental illness or suffering the disabilities which come with old age (3), (4).

As our own experience suggests, community health initiatives like those described in this report, although often very modest in scale, have a much wider significance for the major challenges facing health and health care in contemporary Britain.

The precise nature of these challenges requires detailed debate. However some key questions on the health policy agenda can already be identified:

- The World Health Organisation's 'Health for All' strategy underlines the importance of individual and collective public participation in shaping health care; how can this objective best be achieved in the bureaucratic and highly professional structure of British health services?

- When resources are failing to keep pace with rising demand, what strategies are required to improve the quality and relevance of local health services and maintain public support for the NHS?

- In an increasingly divided society, how can endemic inequalities in both health and access to health care be countered?

- What organisational changes are required in the complex machinery of the NHS and other public agencies if preoccupation with curative services is to be balanced by greater attention to health promotion and to providing caring services for people with chronic disabilities?

- If the transition towards 'community care' is to be more than rhetoric, what investments are required to develop the partnership between professional services and new networks of informal support?

What this report provides is a wealth of experiences and insights from the community health movement in which some responses to these questions might be found. In the pages which follow there are examples of new approaches to public participation in health, the development of more effective partnerships between the providers and users of health services, and the emergence of front-line professional roles more supportive of the aspiration that ordinary people should achieve greater control over their own lives. Some projects demonstrate how the NHS and other public agencies can be brought nearer to the experience and wishes of local people so as to provide a more informed basis for the planning and provision of services. A strong theme in several initiatives is the concern to overcome past inequalities in access to health care. More generally, community development strategies suggest ways of re-negotiating the status of black and other groups who are discriminated against in many aspects of their lives by virtue of their race or class. They also suggest approaches to regenerating a stronger sense of community in localities, typically urban working class areas, which have suffered from a lack of commitment at government level to countering the dislocation, decay and isolation which are the result of social and industrial change.

These experiences and insights need to be examined critically however, considering the rather less encouraging context in which community health projects have to survive. Viewed against the scale of the challenge, the investment in community health initiatives has so far been small. While much has been learnt about the strategies and relationships required to foster community development in health, much is still problematic. Even well established local projects typically exist in a stimulating but uneasy partnership with the NHS. Community initiatives can easily become marginalised where managers and professionals retain paternalistic attitudes or are preoccupied with imperatives stemming from the search for greater efficiency. As another King's Fund monograph (5) has recently argued, the wider political climate has made the whole concern with public participation perhaps more important but less fashionable than it might have been a decade ago. Despite imaginative and painstaking development over the last five years, therefore, the community health movement remains fragile.

One aspect of this fragility relates to funding. Most initiatives to date have lived a hand-to-mouth existence on short-term funding, from the urban programme and charitable trusts. While this may have advantages in promoting innovation, it is a less than adequate basis for encouraging real community development in health. Building public awareness and new forms of action on health issues takes time, especially in disadvantaged communities. It is only in the more enduring projects that careful planning and evaluation (the need for which is recognised by projects and funders alike) are likely to be possible. The insecurity of short-term funding ensures that a substantial part of a project's energy goes into raising funds rather than essential project work. There is therefore an urgent need for existing funders to reconsider their practice of funding community health projects for periods often as short as one or two years. New sources of funding need to be found. And a further crucial consideration is whether health authorities should themselves be long terms sponsors of community health initiatives. Since many projects will be questioning the status quo, the challenge to the NHS is to find ways of offering relatively secure financial support to such initiatives without damaging the autonomy they will need to grow from the community.

In addressing the confusions around community development in health, this report should provide a useful guide to what has been learnt since the first King's Fund conference on this topic five years ago. The way the insights from this work are used will help determine how far the aspirations of ordinary people are influential in the way contemporary challenges to health and health care are tackled.

David Towell

King's Fund College
February 1985

# References

1. Health and Community Work: Some new Approaches
King's Fund Centre Conference Report, 1980

2. Race and Employment in the NHS
King Edward's Hospital Fund for London, 1984

3. People First: Developing services in the community for people with mental handicap
King Edward's Hospital Fund for London, Project Paper 37, 1982

4. Advocacy: The UK and American Experiences
King Edward's Hospital Fund for London, Project Paper 51, 1984

5. Public Participation in Health: Towards a clearer view
King Edward's Hospital Fund for London, 1984

# What is community development in health?

# CHAPTER 1

Pensioners' Link swimming class

# What is community development in health?

What is community development in health? Simply, it is the process by which a community defines its own health needs and organises to make these needs known by service providers in order to bring about change.

As this description may suggest, community health development is something that rarely happens within the framework of the NHS, although some authorities - Oldham, Camberwell, and West Lambeth (see below) - have begun to examine ways of using the community development approach in making community primary care services more reflective of and accountable to local communities.

Within the NHS, the term "community health" is used in quite different and specific ways in community health services units and departments of community medicine. To quote Alison Watt's paper to the conference:

> "A department of community medicine is concerned to use the principles of epidemiology; that is, the identification of patterns of illness and their relationships to particular sections of the population to measure and meet the needs of the community it serves. Similarly, a community health service unit is responsible for the delivery of health services that are located within the District's community, but are neither hospital nor primary care based. Therefore programmes concerned with immunisation, family planning, child, dental and school health services will generally be based within each District's community health services unit and a number of health education units are developing practices of community based health education. It can be seen 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 that health professionals have either failed or decided not to address." (1)

In community development in health the emphasis is on collective action to redress inequalities in health and in access to health care. In these tasks a group or community is aided by a community health worker. As Alison Watt described in her conference paper, a community worker:

> "Has the specific function of enabling a local neighbourhood or estate to become more involved in seeking improvements in that particular community and in the quality of their lives within it. 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 will typically be employed by a voluntary organisation such as a neighbourhood centre or settlement which may be in receipt of charitable funds, or by a public authority such as the health or social services who may be using funds from the Urban Programme or Joint Funding. Usually they will be managed by a group that is composed largely of the community's residents, but depending upon their source of employment they will be accountable either to the line manager or group of professionals in the public authority or to management in the voluntary organisation.
>
> There is no uniform path that a person has to follow in order to become a community worker or a community health worker. Some have come to community work through voluntary activities in their own community and some through their experiences of community action. Over half have formal training in community work. Professionals interested in community development, such as health visitors obviously hold health training. Whilst it is impossible to give more than an overall impression of the routes to community work it is worth remembering that the work is highly 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." (2)

Given this particular approach to health and the needs of health service users, what is the history of the community health movement?

It finds its origins in the social action programmes of the 60's and 70's and the growing awareness of the effects of poor housing, unemployment, poverty and environmental conditions on the mental and physical health of working class communities. It finds inspiration from the Women's Movement in defining needs, supporting self help groups and challenging control in the delivery of health care. It is also firmly based in those forms of community activity which challenge the power of the corporate state and its inhuman vision. Community health projects were first established in the late 1970s when it had become clear that in the absence of democratic channels, alternative ways of engaging the NHS in realising its responsibility to the health needs of local communities had to be developed. Helen Rosenthal from London Community Health Resource describes the growth of health as an issue of public concern:

> "The NHS has never been open to forms of democratic control, and people's experience of it is personal and private. Ill people are often reluctant to complain about the treatment they receive. Ill people made better are often grateful and eager to forget. Ill health itself is often fatalistically accepted. Thus neither the NHS nor illness itself has appeared to be open to influence and change by the collective action of people in the community. In the last four years, however, this situation has changed and health and health service provision have quickly become areas of importance for community workers. The Women's Movement, the unionisation of health and hospital workers, the reorganisations and cutbacks in the NHS and the radical movements in public and environmental health have all become important forces in creating new awareness that health and illness are indeed

> issues for public and collective concern. Community workers have both responded to and helped to create this awareness." (3)

Of those pioneering projects which are still in existence today, the Albany Health Project attached to the Albany Social Action Centre (in Deptford, south-east London), was funded initially by the Foundation for Alternatives as an action research project on the role of community work in health education; Health in Homerton (in Hackney, east London) was an initiative of City and Hackney Community Health Council; the Waterloo Health Project (in Lambeth, south-east London) developed from the work of the Waterloo Action Centre; the Bethnal Green Health Project at Oxford House Settlement (Tower Hamlets, east London) grew out of the community worker's work with women, the elderly, and Tower Hamlets CHC. As well as having certain principles in common and being based in working class, inner city areas, most successful projects such as these are attached to centres which are already a focus of community activity and in that way obtain local managerial and supportive involvement.

If there appears to be a bias towards London projects, this reflects the fact that London is probably better organised in terms of community development. The Greater London Council and the Inner City Partnership areas have provided useful sources of short-term funding, and the London Community Health Resource was set up in 1981 to play a supportive and developmental role towards health projects in London. Nevertheless, there are well established projects in Newcastle-upon-Tyne, Bradford, Mansfield, Liverpool, Renfrewshire and Glasgow, (some of which will be described in this report), and the Community Health Initiatives Resource Unit (set up in 1983) will play a growing part in supporting projects outside London.

# The principles of community development in health

Most community health projects have broadly similar guiding principles. The following set of principles drawn up by the Waterloo Health Project are representative of those of many projects.

1) To promote an interest in and an understanding of positive health as defined by the World Health Organisation (a state of physical, mental and intellectual well-being)

2) To develop a collective approach to health

3) To promote self-confidence

4) To enable greater access to health information and resources

5) To promote positive changes in relationships between health professionals and local people

6) To encourage local people to identify their health needs and to articulate them

7) To influence policy at a local level; thereby creating a more responsive, democratic and sensitive delivery of health services

8) To identify and influence factors affecting health

9) To share the experience of the Project with a wider audience

Within these principles are three common themes which guide the practice of the community health movement, namely concern with:

1) The social causes of ill health

2) Unequal access to health care

3) The challenge to health care planning and provision.

How do community health projects develop these principles and broader themes in terms of practice and action? The projects that presented their work to the conference were all attempting to answer this question, and the welter of ideas and information that they gave suggests that the answers are many and complex.

In the next section (pp17 - 59), we have organised the conference material under the three themes identified above in an attempt to understand better the shared basis of apparently diverse initiatives. Within this framework the texts of two of the conference addresses are included in order to amplify further two crucial issues raised by several of the projects, namely racism and the relationship between community-based projects and the NHS.

# The social causes of ill health

## CHAPTER 2

# The social causes of ill health

A major concern of the community health movement is to develop collective awareness of and action about the social causes of ill health and its counterpoint, positive health. In other words, projects often go beyond an analysis of the role poverty, racism and the material conditions of existence play in the health of communities, to a critique of the individual and disease based models of health on which the NHS is organised.

## What is health?

Project workers attending the conference stressed the importance of looking afresh at what constitutes health for a particular group. For these projects, arriving at a definition based on people's perception of their own health needs is a long process which involves looking at attitudes to health and the effects these can have on our ability to assert our own health needs. Questions such as - are we really to blame for our own ill health, the accidents our children have, the difficulty we have giving up smoking, are discussed in a group setting. When groups do arrive at their own definitions of health they can be surprising. Waterloo Young People's Health Project came up with 'a good diet, open space, trips to the country and less grey concrete'. These ideas formed the basis of a health education programme on nutrition, dental hygiene, meetings with the Environmental Health Officer and making an exhibition on the environment in Waterloo.

The Ormiston Road Centre for mental health in Greenwich sees health as

> "A state of complete physical, mental and social well-being and not merely the absence of disease." The 1982 Annual Report continues "With this WHO definition in mind we decided to run a series of Well-being Workshops. The idea was to offer people an introduction to self help methods of health.

> We wanted people to have the chance of coming together to explore some of the issues involved in maintaining their own health. We initially chose twelve aspects we considered to be under the umbrella term of 'well being', examples of which were self-assertion, welfare rights, massage and co-counselling. The Workshops attracted a variety of people, some who use the centre already, others who knew us by name only, and others for whom this was also an introduction to the whole concept of mental health.
>
> There are numerous aspects of life which either subtly or overtly deprive people of well being. People can increase their awareness and ability to take care of themselves, and have the confidence to believe in what is right for them."(4)

At the conference the workshop on Pensioners' Health, given by Brent Pensioners Link, the Bethnal Green Health Project and Age Concern Lambeth (see page 35) explained the importance for pensioners of defining for themselves what health means for them.

## Pensioners organise

Inequalities in Health: the Black Report (5), has this to say about old age in the chapter 'Towards an Explanation of Health Inequalities'.

> "Health may literally become a matter of life and death for the over 65s. The bodies of men seem to exhibit the effects of wear and tear sooner than those of women and those of manual workers sooner than those of non-manual. What has to be remembered is that these outcomes are the end product of inequalities in the use made of, and the demands upon, the human body earlier in the lifetime and the kind of environment in which human beings have been placed. This interpretation suggests that inequalities in health are the direct reflection of inequalities in the social division of labour. But

> inequalities in health at the end of the lifetime also emanate from the distribution of rewards associated with the social division of labour. Old age is a time of poverty, albeit poverty expressed in the form of relative deprivation, which among Britain's aged can mean material scarcity in very real terms, as deaths from hypothermia among the old reveal in severe winters. In old age the relationship between income and the capacity to protect personal health is stronger perhaps than at any other time in the life-cycle, and in general it is likely that individuals who are well endowed through generous or index-linked pensions schemes will lead the healthiest, the most comfortable and the longest lives after retirement. These material fortunes or misfortunes of old age are closely linked with occupational class during the working life. To have secure employment and an above average income when one is at work is to be better able to provide for one's retirement. It is in this way that continuity in the distribution of material welfare is sustained, and inequalities in health perpetuated, from the cradle to the grave."

The pensioners involved in Brent Pensioners Link, an organisation which supports a number of pensioners' action groups have combined this analysis with an understanding of how crucial social contact is for maintaining a sense of well-being amongst pensioners and for ensuring that pensioners do receive health care when they need it. For them, illness amongst pensioners cannot be seem simply as an isolated medical problem and so the factors seen as contributing to positive health go beyond the medical model.

South Kilburn Active Pensioners Group (15 per cent of South Kilburn households contain single pensioners living alone) see access to public services, friends, and holidays as part of living a healthy old age:

> "Pensioners are very aware of how things like the level of pension and poor public transport affect their health. Being on a pension for many people means you cannot afford to heat

> your home properly, you have to buy the cheapest food and you cannot afford a holiday." (6)

Kilburn and Dollis Hill Active Pensioners are being supported in their campaign for a higher pension, the abolition of standing charges, particularly on heating, better public transport and the retention of the travel pass. As well they are involved in local campaigns - concern with the state of street pavements in Kilburn which had caused injury to pensioners led the group to organise a grand tour with the district works officer and the press. The pavements were repaired.

Pensioners Link also runs a health education group for pensioners in the Carlton Centre on a lonely modern high rise estate. They see it this way:

> "Ill health places severe limitations on elderly people. Being ill often means you have difficulties getting out of the house, you lose contact with your friends, it places a strain on your limited finances, you may need extra heating or a special diet, you may feel useless, worthless and dependent. Because health problems and disability are so prevalent among elderly people, there is a great interest and thirst for information about health. What makes you ill? Is it just my age? Do these pills really do any good? What are the side effects? What can I do to help myself?" (7)

Course topics have included: bones and joints, looking after your feet, waterworks, getting the best from your doctor. As well as being a contact point for pensioners, these courses increase their self esteem and confidence when dealing with the health services.

A tenants' association in Brent has successfully campaigned for funds to convert a room on their estate into a small day care centre for pensioners. Because of the social composition of the area this tenants' association is made up entirely of pensioners who are only too aware of the need for support and care for their age group.

> "Over the last year, three (of our members) have suffered from the loss of a husband or wife, two have had serious illnesses requiring lengthy stays in hospital, two have had accidents resulting in fractures and two have died." (8)

As well as providing day care for their frail elderly community the tenants' association also provides support to the isolated housebound elderly.

Finally, Pensioners Link is involved with Brent CHC's Pensioners' Health Group whose work in trying to improve health services for pensioners complements the action groups. The group has been active in campaigning for a better chiropody service in Brent knowing that a lot of isolation and confusion can result when foot care deteriorates. They did a survey of pensioners' groups, wrote to the newspaper and found that many pensioners were having difficulty getting access to the service. They held meetings with the district chiropodist, kept up pressure through the press and succeeded in improving access for pensioners. Application forms for chiropody became freely available at health centres and clinics, another telephone line was installed in the chiropody department so that the chiropodists could be directly contacted, and chiropody duties were reorganised so that more patients could be treated.

In London's East End, the <u>Bethnal Green Health Project</u> grew out of interest in health fostered by the community worker at Oxford House Settlement. Such was the interest in Women's Health Days and Pensioners' Health Days that she agreed that Oxford House obtained a three-year grant for her to expand on her work as a community health worker.

One of the crucial aspects of this post is the link the worker has with Tower Hamlets CHC (she is their current chairwoman). For pensioners who are directly concerned with the increasing inaccessibility of health care in a district with a high rate of hospital and casualty closure, this link is a major source of information, support and campaign back-up.

The community health worker set up a health information stall in the Bethnal Green market on Wednesdays and Fridays. The stall quickly became a listening post: pensioners using the stall got together to attend health courses run by the project. From this the Pensioners Health Group was formed. Its aim is to support pensioners in acquiring healthier habits such as eating properly and getting exercise. Starting with floor exercises, the group now plays netball, organises its own outings and holidays and has formed close ties with Tower Hamlets Pensioners Action Group campaigning for the rights of pensioners throughout the Borough.

# Unequal access to health care

## CHAPTER 3

A pensioner enjoying a vegetarian Indian meal at the Millan Centre Luncheon Club, Wandsworth

# Unequal access to health care

Closely tied in with the issues of positive health and social causes of ill health which these groups are tackling, is the problem of unequal access to health and health care. In the Black Report these inequalities are firmly ascribed to structural issues of class and race, and the report quotes Julian Tudor Hart's famous passage on the inverse care law:

> "In areas with most sickness and death, general practitioners have more work, larger lists, less hospital support and inherit more clinically ineffective traditions of consultation than in the healthiest areas; and hospital doctors shoulder heavier caseloads with less staff and equipment, more obsolete buildings and suffer recurrent crises in the availability of beds and replacement of staff. These trends can be summed up as the inverse care law: that the availability of good medical care tends to vary inversely with the need of the population served." (9)

Community health projects are attempting to redress the balance on a very local level - by helping people to redefine health needs and trying to effect changes in the nature and delivery of health services to meet those needs. This may range from a concern with the individual's relationship with her GP to challenging the assumptions behind the running of an entire institution. A major focus of activity is race and health, and two projects, Training in Health and Race, and Age Concern Lambeth gave the conference an illustration of their work in this area. A second major focus for projects is mental health and disadvantage, and five projects presented illustrations; advice projects based at Tooting Bec and Springfield Hospitals, the Brent Black Mental Health Project, the Ormiston Road Centre, and the Waterloo Counselling Project.

# Race and health

The Black Report comments briefly that a consideration of race and health would demonstrate the inverse care law - if an adequate number of studies were available. In perhaps the strongest statement it makes on race, the report admits that there is

> "a clear lack of adequate facilities in some of the areas in which (the black community has) been obliged to congregate." (10)

In addition, however, the NHS is still a long way from being receptive to the needs of different racial and cultural groups. These difficulties are compounded for those groups who are additionally isolated because of a language barrier. In recent years different racial and cultural groups have been waging a struggle to convince service providers that problems of access are not simply to do with locality and opening times. Black and ethnic minority groups on a local and national level are now demonstrating that access is as much to do with making a service acceptable and sensitive to different needs. In the past two years the number of community health projects working exclusively with people from the racial minorities on this very issue has grown enormously, particularly in London.

In Islington, (following the Hackney model, page 55.) the Turkish Women's Project is offering ante and post natal education to pregnant women and those with new born babies; in Haringey, the Black and Ethnic Minority Link Workers' Project is employing women to act as advocates and interpreters for women using maternity services; the Tower Hamlets Maternity Services Liaison Scheme has a similar role; the Greenwich Black Women's Project has just produced a report, Black Women and the NHS. But challenging institutionalised racism successfully can undermine the continued livelihood and viability of these projects, since the funding organisations, Partnership Committees, and even ethnic minority working parties within health authorities will often be permeated by the same institutionalised racism.

This conundrum was explored at the conference, when Shaama Saggar-Malik from Training in Health and Race looked at some issues relating to community health initiatives in the black and ethnic minority communities.

> "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 single 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 the 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 was interesting to note listening to the previous speakers that only one mention was made of the black and ethnic minority communities as 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 along 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, <u>should</u> 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.

Three of them work in the community. Where are the black decision-makers? Who holds the power and who actually makes the decisions are critical. 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 with health. Yet when I approach funding agencies, they in turn say 'we 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 responses 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:

a) identifying the community's health needs

b) reponses to these needs

c) constraints and difficulties experienced in developing black and ethnic minority community health initiatives

d) why it's important to support these initiatives

## a) <u>Identifying the community's health needs</u>

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 Black Report 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 it isn't always. Very often our health needs are defined for us and in 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 Asian women who may be on that balcony and living in high-rise flats just like their white counterparts? 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. 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.

### b) 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 minority 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. /

### c) 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 non-political. 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. What is 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 becomes 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 re-fund you.'

### d) 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 on 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 do that counts."

Training in Health and Race, an organisation with a national network, was established in September 1982 by the National Extension College, with a three year grant from the Health Education Council. The overall aim of the project is to work towards a health service more responsive to the needs of a multiracial society through the provision of training and training materials for health workers. To achieve this aim the project is engaged in researching training needs, and finding effective ways to incorporate the training and materials into the work of trainers, tutors and other health educators. Training in Health and Race is also committed to increasing community awareness and involvement in health issues and has funded and advised numerous community health initiatives across the country.

Within the community development movement some organisations which have predominantly catered for white people are beginning to examine their own racist biases.

Age Concern Lambeth, based in Brixton, has recently been criticised with some justification for not meeting the needs of minority ethnic groups. The project has undertaken to remedy this, beginning with a booklet about all the services, statutory and voluntary, in Lambeth, in five Asian languages. It has also increased the range of cheap food sold to pensioners to include spices, chapati flour, rice, pulses and many other items in order to provide a service more appropriate to a multi-cultural society. Age Concern staff have engaged the help of local ethnic minority groups to examine the organisation's racism and to take positive steps to reach and work with a wider range of black groups in the area. Staff have recently attended a racism awareness course and a group has been formed to monitor the issues raised at the workshop. Staff and members of the management committee have recently met to reassess Age Concern's work with ethnic minority groups and plan to continue to monitor the organisation's policy and practice. Attempts are being made to increase the number of volunteers from black groups - and there have been encouraging results. One service, for example, food sales, which until recently was run by a small group of white volunteers, now includes over one third black volunteers from Asian, African and West Indian backgrounds. There are are five black counsellors on the bereavement counselling scheme but as numbers are still low, some sessions are set aside in the bereavement counselling support groups to educate volunteers about the meaning of death and bereavement in different cultures. These sessions are conducted with the help of volunteers who are from different ethnic minority groups.

Age Concern's community worker is responsible for ensuring that the needs of each ethnic minority group are adequately serviced in the organisation's community development and outreach work. She makes available to black groups the contacts, skills and capacity for support that an organisation like Age Concern has built up over many years in the area. This support aims to increase black organisations' independence by helping to unscramble the complexity of local authority bureaucracy for those who have not come across these difficulties before, for example how to fundraise and find premises. Through this work the Fifty-Plus, a West Indian club, was helped to obtain a grant from Age Concern England for their music group; the south London branch of the UK Asian Women's Conference found a meeting place in Streatham through Age Concern's connections with Imanuel Church. The Seventh Day Adventist Church Day Centre, a West Indian Pensioners' club, was put in touch with the adult education service so that they could arrange keep fit and art classes and the necessary materials. Ashram, an Asian elderly day centre, gained support and back-up, in its search for funding and suitable premises. These relationships are mutually beneficial and Age Concern has gained tremendously from the advice, information and support offered by groups working specifically with black pensioners. These groups help to recruit volunteers for Age Concern and played a major part in the Pensioners' Health Day - a day of activities, stalls and information sponsored by Age Concern. Although there is still a long way to go, Age Concern has made a start.

# Mental health and disadvantage

Several studies (11) in recent years have posited a stong relationship between mental illness and social and economic conditions. Two of the most recent studies, Unemployment and Mortality (12) and Unemployment, Health and Social Policy (13) assert that poverty, stress and the stigma of unemployment may account for the high tendency to commit suicide (unemployed men in the OPCS sample were more than twice as likely to have committed suicide than employed men of the same age) and to diseases such as cancer amongst the unemployed.

Not only has there been inadequate recognition of the causes of mental illness in the practice of mental health services, but they are traditionally under-resourced and people suffering from mental illness have traditionally had their needs defined for them. The one is a product of the other insofar as the necessary variety of services, particularly preventative services, is not available to the mentally ill. But in addition, mentally ill people are particularly powerless and are still largely victims of stigma, fear, lack of imagination and a closedness of mind both within and outside the service. All these factors mean they have less than fair access to a less than adequate service and once in receipt of care often have less than equal access to their statutory rights.

In the Workshop on Mental Health, five projects spoke about the work they are doing to redress some of these imbalances.

Workers from two projects, Tooting Bec Hospital Citizen's Advice Bureau and Springfield Hospital Advice and Legal Representation Project talked about the work they are doing with patients and their rights in the hospital setting. Both hospitals have high proportions of elderly and long-stay patients for whom access to advice and help in sorting out practical difficulties can improve the quality of life in hospital, relieve stress and even assist rehabilitation and discharge from hospital. Because of this the projects see themselves as part of the network of community projects concerned with the lives of mentally ill people, their support, and the education of those coming into contact with them. Both work in a training capacity with staff on take-up of benefits, the Mental Health Act, and welfare rights. Both projects are funded independently of the hospitals in which they are based - this gives freedom to take up controversial issues, but at the same time places emphasis on gaining the confidence and goodwill of staff.

Tooting Bec Hospital Citizen's Advice Bureau offers a free, confidential and impartial service to patients, their relatives and staff. The advice worker runs two open door sessions a week and is available for sessions on wards. The majority of the 80-100 enquiries she receives every month (there are 850 people in the hospital) require advice on financial matters. Particular characteristics of the hospital environment add to the uncertainties of an already problematic state benefit system and patients and their families frequently face more administrative problems than other claimants at a time in their lives when they are perhaps least able to deal with them. The project has a dossier of cases illustrating these problems and has set up meetings with the hospital managers to try to resolve some of the internal difficulties.

The Springfield Hospital Advice and Legal Representation Project is a sub-office of the Wandsworth Law Centre. It has its own management committee of local people who employ the two advice workers and one solicitor. The project does a lot of court and tribunal work relating to matrimonial, child care, criminal, consumer, financial and housing matters, in addition to Mental Health Act work and rights training for staff and patients. It is currently involved in a review of how the hospital deals with patients' money.

The project is being evaluated by the Nuffield Foundation through interviews with patients and staff. This is due to be completed by March 1985.

The idea for the Brent Black Mental Health Project came from two black neighbourhood development social workers who were appointed to meet the needs of the black community in neighbourhood patches. Part of their brief was to work with the black mentally ill. They were concerned when they visited Shenley Hospital in Hertfordshire, (the catchment area mental hospital for Brent District Health Authority) at the apparently disproportionate number of black (young) people being admitted to Shenley Hospital, and the nature of the treatment they were receiving. As well as this 'new' group they were also concerned at those who could be classified as 'old' long-stay patients. They noticed too the social and cultural isolation suffered by both the old and new groups of 'patients'.

They determined to do something about this state of affairs and approached the hospital authorities about setting up a befriending project in the hospital, as well as the community. Funding was sought to employ a co-ordinator for 20 volunteer befrienders, working both in the community and hospital. A management committee was set up, which currently includes among its members a black social worker, a race relations advisor to Brent Social Services (both founder members of the project), a health education officer, and a local volunteer bureau organiser. The project is also now setting up an Advisory Panel to advise the project on the development of its work.

Befrienders from the black community can have a significant impact on a patient, wherever he or she has been referred from. The project seeks befrienders with skills, tolerance, patient and love to support Mr X or Ms Y through a period of mental illness. Support is an important link for a person in hospital or the community. A befriender can be a true friend, or act as a catalyst in some cases. A befriender can also provide a very critical and useful role in judging Mr/Ms X or Y's development. Whether health professionals would be willing to accept such an assessment is another matter.

A wide range of issues, such as social security, housing, education, personal relationships and employment can arise. Dealing with these issues obviously stretches the befrienders, but it is important for them to be clear where they are able to offer assistance. Drawing a line means developing links with voluntary and statutory agencies, in order to offer adequate support to befrienders, but also meet the needs of the black community.

Over the next four to five years, the project hopes to develop groupwork with befrienders, relatives and friends; to expand opportunities for befrienders inside and outside Brent; and to make an input, as yet undefined, with the introduction of a Care in the Community package for the mentally ill. Two other mental health projects spoke in the workshop about the gaps which as voluntary projects they found themselves filling in their districts' less than adequate mental health services.

The Ormiston Road Centre in East Greenwich was established five years ago by Greenwich MIND to meet the need, in the London Borough of Greenwich, for a "facility less formal and less structured than the local authority day centre - a safe supportive place, in effect an asylum in its true sense" (14). As well as aiming to support people vulnerable to mental illness living in the community, the centre aims to educate the public about mental health and promote good mental health. The centre is organised according to community work principles - that is as part of its therapeutic role the centre encourages users to play a major part in its running. For example, a person may call for individual counselling, become a volunteer driver and join the management committee, which is elected by centre users.

The centre thus has flexibility, informality and a variety of users and problems that would not be found in a local authority or health service centre.

As an example, one of the four paid workers outlined the centre's weekly programme to the workshop.

Monday: Relaxation group (leader provided by Thamesside Adult Education Institute
Agoraphobic self-help group

| | |
|---|---|
| Tues/Weds: | Group for elderly confused people (helped by Age Concern volunteers)<br>Social evening |
| Wednesday: | Group for elderly confused people<br>Assertiveness course |
| Thursday: | Drop in; co-counselling<br>Alcohol advice session |
| Friday: | Well-being workshop (open to anyone)<br>Women's health group |
| Sunday: | Minibus group (for relatives of patients in Bexley Hospital)<br>Sunday tea (for all centre users) |

In addition individual one-to-one and telephone counselling is available, as well as time and space for people who just want to sit and feel safe. One of the centre users describes the centre's positive attitude to mental health in a very personal way:

> "I first came to Ormiston Road about mid-October 1982. I had felt desperately lonely and cut off, so it was extremely difficult to enter the building for the Thursday 'drop in'. I had come twice before, but could not make that first step of entering the door. When I finally arrived I found the volunteers, staff and other ex-patients were friendly and they made me feel welcome. I soon realised it wasn't all groups, and that it was informal and that if I wanted, I could play cards, chess, or numerous other games or just listen to music and have a quiet cup of coffee or tea and a cigarette. With the support of the staff and volunteers I soon came out of my shell and started helping a little, perhaps washing up at the end of the day, or just emptying ash trays. One day Kathy asked me if I would fix some 'fire exit' signs on two of the doors. I agreed but afterwards felt frightened and incapable of this, and after putting this task off for a few weeks, very

> apprehensively set about it. I accomplished this task and received much praise, which gave me tremendous confidence.
>
> This new found confidence has since enabled me to regularly help behind the 'bar' making tea and coffee for those in a similar situation I had been in six months previously. From this experience and the Assertion Group run at the centre of a Thursday evening, I have at last felt a useful, needed and valuable human being."(15)

The Waterloo Community Counselling Project also arose in response to unmet demand and a lack of low key mental health services in Waterloo - a working class area of pre-war estates and urban blight in the lee of a prestigious teaching hospital, St Thomas'. Workers in the Waterloo Action Centre were aware that people coming for advice often needed more time to talk over problems than they could give; women attending the women's health group supported by the Waterloo Health Project were also concerned about mental health issues. The Health Project held a public meeting in June 1981 at which it was agreed that a mental health drop-in should be set up. Because of the close relationship the Health Project had with the health authority, the drop-in opened immediately at the Barley Mow Clinic on a local council estate on Tuesday evenings from 7.00 - 9.00 pm.

The project is organised on community work principles. The management committee comprises half local representatives, half counsellors. Decisions are made jointly. Trained counsellors are employed by the project, but one of their central tasks is to train local people working on the project in counselling skills. The project aims to break down barriers between lay and professional people. Another of the goals of the project is to promote good mental health in the Waterloo area - the drop-in can only achieve a tiny part of this. Project workers have decided therefore to offer consultation to workers in local community organisations, for example the mother and toddler group, to visit local groups to talk about the project's work, to set up courses on befriending and counselling skills, and to attend local fairs, exhibitions and fun days.

When the project started in 1981, it offered an evening "drop-in" session, but women and elderly people who were afraid or had difficulty in getting out in the evening were unable to use the session. Since November 1982 one-to-one counselling on an appointment basis has been offered by the project. This has been well used despite the fact that project workers are concerned that being based in the clinic, it may be seen by local people as another health service session. To counter this the management committee is considering moving to a more central, informal venue for individual counselling, whilst increasing the daytime use of the clinic to run groups which would reach women who are calling in for family planning and the baby clinic and pensioners who come for health check ups and chiropody.

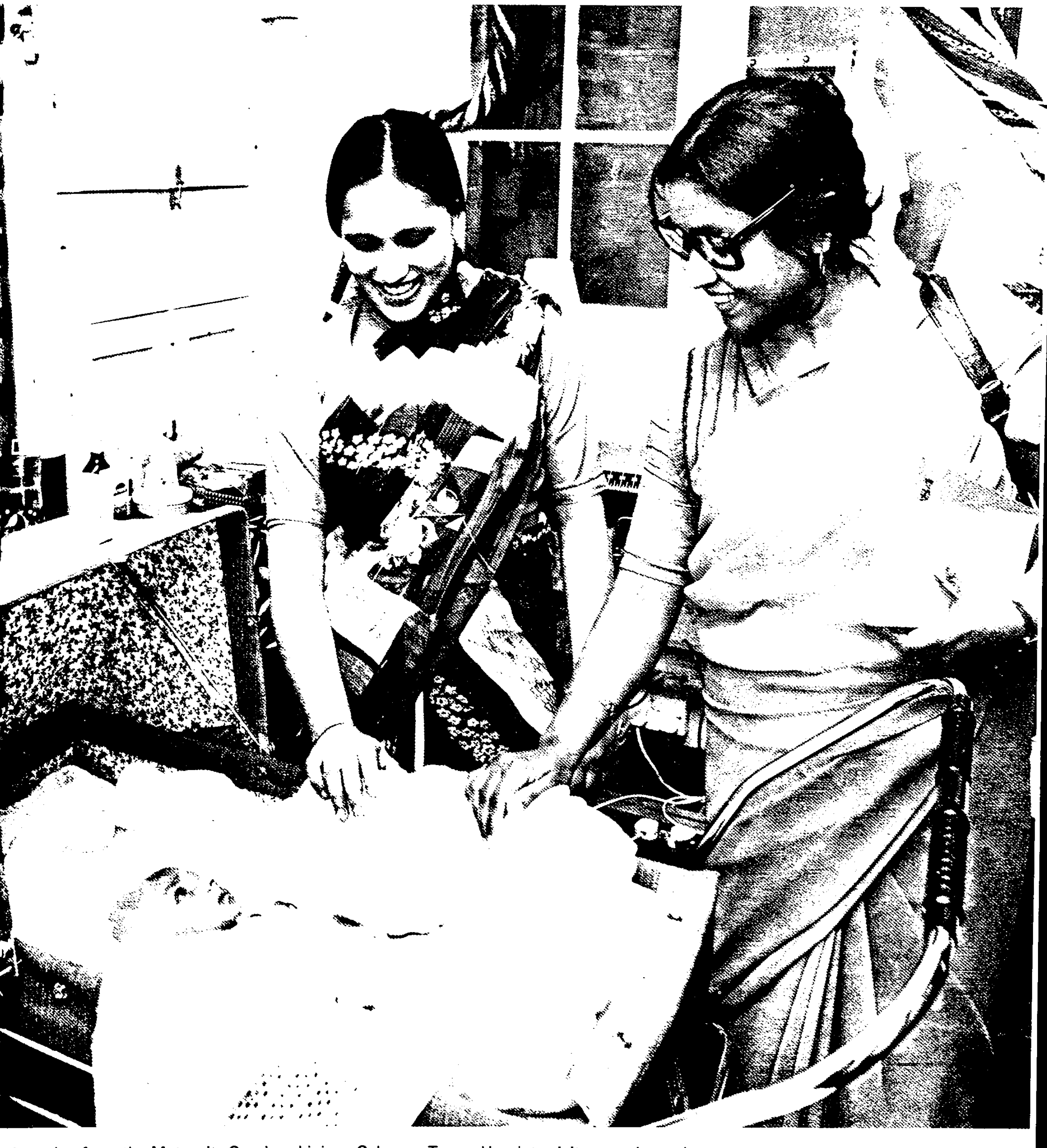
The project helps people with a wide range of problems for which there is practically no appropriate help in the immediate area. The only mental health service is in St Thomas' Hospital where there is a daily psychiatric service, a community psychiatric nurse who complements the hospital's work, and social work and GP help. All these services work closely with the project and make referrals. The following sorts of problems have been brought to the project; personal (such as bereavement, depression); lifestyle (gambling, alcoholism); medical (drug addiction, terminal illness); race; relationships and sexuality. Lay and trained counsellors attend monthly supervisory sessions.

One of the not uncommon difficulties the project has experienced is operating on a shoe string budget which denies the project both continuity, and a regular contact person in its catchment area. Being available two hours a week from 7.00 - 9.00 makes the project rather inaccessible, and creates problems for people who want to make referrals by day. Such a tight budget burdens the counsellors and management committee members heavily to do publicity and public relations work in their 'spare time' - again a less than efficient way of making the project known. The project urgently needs administrative support.

Although offering care and support to people who would not otherwise receive it, these projects do not see themselves simply as plugging gaps in the NHS. They all believe that the flexible and non-stigmatising way in which they offer their care could not be done within the NHS as it is presently organised. They hope they are setting an example of the sorts of services which are in demand and how they could best be provided. In the meantime their continuing autonomy is crucial to their success.

# The challenge to health care planning and provision

# CHAPTER 4



A worker from the Maternity Services Liaison Scheme, Tower Hamlets visits a mother at home

# The challenge to health care planning and provision

Whether projects tackle the issues of inequality by providing additional means of support for people, by helping people make their needs heard, or by campaigning for improved services within the NHS, they are above all throwing out a challenge to health service managers and providers. They are inviting decision makers in the health service to examine the basis on which decisions are made, to consider how best to obtain the information to meet the needs of a changing society, to think again in whose interests they are acting and about to whom they are accountable. As David Towell said at the conference:

> "Over the coming years the NHS will be facing the challenge of building and sustaining the community, shifting priorities from cure to prevention, and being responsive to local needs in both these activities. The Community Health Movement has great relevance for these challenges."

Dr Robert Morris, District Medical Officer from West Lambeth Health Authority spoke to the conference about the stimulating if uneasy partnership with community health projects that his authority felt was crucial to the development of its community based policies. His paper, entitled <u>The Need for Community Development in Health</u>, is given here in full.

> "The purpose of my paper today is to give you some idea of the reasons why I, as a District Medical Officer of an inner city Authority, see a need for community development in health. My starting point I suppose should be my conversion to a belief in the innate right of people to be involved in activity which influences their health. The World Health Organisation in its <u>Global Strategy for Health for All by the Year 2000</u>, which I feel sure many of you will be aware of and which our government was a signatory to, made the point very explicit:

> '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 incidentally and which is well worth looking at, 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. Both these themes of people's right to participate, of community involvement, are open to misinterpretation, and I would like to clarify my own position a little. 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 different 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 my local population support community health initiatives, and attempt (a carefully chosen word!) to get my authority's agreement to support them through the Inner Cities 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 leaves me frequently 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 real 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 totally 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.

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, from the same sort of area:

> '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 users' experience 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 access to information about the extent of dissatisfaction around whichever issue, nor 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 real people and their experiences. Why should we get close? 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 development project. Unfortunately here, as too often happens, the professional expert opinon may not be shared by those with direct experience. Secondly, we tend to create policy and to devise health 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. For instance, I see great difficulties ahead in Care in Action policies if there is not due attention paid to the real carers in the community and their not inconsiderable 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 the victim-blaming approach of health educators like some health visitors, or ensure that what I like to call the 'style' of our services is appropriate for the people concerned, such as blacks, women or the disabled. 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 peoples' 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.

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 personal ill-health. How do they cope with the problem of wider health issues? The increasing reliance of people over the years on health professionals has been encouraged by those professionals. It is the function of most CHIs on the other hand 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 not be ignored. But in a group it cannot be. It becomes a force which 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. Most indeed seem to be due to social and economic factors. So most health issues can only be resolved in a multi-agency manner, through collaboration of agencies. The community itself is often the only common element between the service agencies, and part of any CHI's 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. 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 safeguarding 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 and 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. In 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 in dealing with, or wish to change in some way, if that is one of the problems.

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 there is some account made of any financial contribution to a scheme that they may make. This may be a regular report, an input to a managerial body, a formal evaluation or whatever.

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 overriding philosophies that we should be following in the health service today if we are together going to get nearer achieving health for all."

In the workshop on Challenging and Linking with Statutory Services, the Waterloo Health Project, the Multi-Ethnic Women's Health Project and the Asian Community Action Group discussed their experiences in relating to statutory services.

Amongst others, three of the aims of the Waterloo Health Project are to make positive changes in relationships between local people and professionals, to encourage people to identify their health needs, and to influence policy at a local level creating a more sensitive and democratic delivery of health services. With these aims in mind the project held a meeting in November 1980 to discuss the Barley Mow, an under-used, under-resourced and anonymous clinic on an inner city council estate. Over a number of meetings, the group drew up and discussed the health related activities they as local users would like to see in the building: such things as health courses, a health library, community dietetic service, ante-natal clinic, pensioners health check-ups, chiropody, a well-person clinic, counselling. To encourage people to make use of the service it was agreed that the atmosphere at the clinic should be informal, that staff should be committed to community involvement, and that local people themselves should be involved in running the clinic.

At the end of April 1981 a meeting, arranged by the Community Health Council, was held with local residents, the District Medical Officer and District Planning Department to discuss these proposals. Gradually a user group was formed from these discussions. It meets at the clinic and comprises clinic workers, their managers and users. The group has a constitution and has been attempting, so far unsuccessfully, to gain recognition as part of the District's planning and management structure.

Despite its informal status, the group has succeeded in having material improvements made to the clinic, and a large appointments board put up outside. They have also succeeded in broadening the range of activities in the clinic. There is now a pensioners health check up, chiropody for pensioners (and another session about to open), and a parents' group. Groups change according to need. Other community groups now use the premises - including the Waterloo Community Counselling Project, and the toy library; and Lambeth social workers do sessions at the clinic as it is more accessible than their area office.

There have, of course, been problems. During the first months there was mutual suspicion and tension between NHS employees and members of the local community. This has broken down to the extent that discussions about different services are enjoyable and stimulating and at times take clinic workers beyond their traditional expectations. For example, one meeting discussed the environmental and social factors affecting women using the baby clinic and the pressures created by poor housing and lack of child care facilities. As a result, local groups have begun investigating the range and adequacy of child care in the area. The user group is a forum where people who would not normally share ideas and experiences are doing just that. The result is a clearer understanding of needs and efforts to adjust the service accordingly.

With its growing confidence and understanding of the issues involved, the group has become more active in commenting on district policy documents, particularly those on primary care, and usually send a representative to observe DHA meetings. Nevertheless the project and local people are disappointed that the user group still has no formal status and no real power when it comes to decision-making or influencing policy at district level. For the local community it is a long and difficult struggle to be accepted as equal partners in the planning and future of the services they know they need.

Often, the process of challenging the content and pattern of health service delivery has the effect of challenging traditional victim-blaming attitudes commonly held within the health service. Current concern with under-use of ante-natal care by pregnant women from the racial minorities is a case in point. As ante-natal care is offered to all pregnant women in this country it is frequently assumed that the responsibility for low take-up of services lies with the women themselves. Whilst recognising that the situation is extremely serious, many authorities are failing in their attempts to 'encourage' women from racial minorities to attend ante- and post-natal care.

In Hackney, the Multi-Ethnic Women's Project has recognised that failure to provide an appropriate and sensitive health service for women from different ethnic minority groups is a large part of the problem. The project, therefore, was set up to work with staff and users at the Mothers' Maternity Hospital. Local women from the Asian and Turkish communities are employed by the project to act as advocates for the women. They attend clinics in the hospital to give support to the mother, and do a home visit after the birth of the baby.

The project is not an interpreting service, although workers have these skills. It has two aims. First, to educate health workers in the hospital about the cultural values and needs of the women and to offer health education to the women using the service; and second, to act as advocates. The overall goal is to improve communication between health professionals and women attending the hospital.

To the project, advocacy means challenging cultural assumptions: asserting the rights of Asian women to be seen by a woman doctor (the project is still doing battle on two fronts: to ensure that enough women doctors are being assigned to the hospital to cover needs, and to establish the policy that women will be seen by one of them as of right); pressing for the rights of Turkish and Asian women to have dietary advice based on their cultural needs; challenging the regulation that all Asian babies have a BCG injection regardless of parents' wishes. It also means ensuring that users of the hospital know what their rights in these matters are.

As well as being a constant, confident, and articulate presence in the hospital, the project also influences the way the service is delivered through its management model. The project is independent of the health service, but its steering committee comprises half professionals (including the hospital's consultant obstetrician) and half representatives from the community. In this way issues of institutional racism can be tackled more effectively.

What has developed could be described as a challenging partnership - and a vastly improved service.

The community health worker attached to Lambeth's Asian Community Action Group was less optimistic about her ability to challenge racist attitudes and health service treatment of ethnic minorities in West Lambeth Health District. As the only Asian community health worker in the district she said:

> "I feel my appointment is only a superficial solution to the problems in the health service and that provision must be made for resources such as interpreting and link work. I

> myself have been asked to perform an interpreting role. Having an Asian worker provides an 'easy forum' for health professionals, because they have an interpreter there, whereas it is really a question of attitudes and training of health professionals such as health visitors."

She felt developing self help groups which would eventually be able to raise issues for themselves is more likely to be the way forward for the Asian community than, for example the health visitor deciding diet or ante-natal care is the problem and the service being reorganised accordingly. This she felt is the real challenge, one which most authorities would have difficulty in meeting given their lack of confidence in the Asian community.

After these presentations, workshop participants discussed the training needs of health professionals who wished to improve service delivery by recognising the importance of engaging with local people in planning and monitoring the service.

It was stressed that although change is initiated by pressure from consumers, health professionals need to recognise their responsibility in giving local demands credibility, particularly if a pressure group is representing a group of people who are elderly, ill, or lacking in energy to push changes through. Participants looked at the need for more training in counselling skills, how to deal with problems; the need to develop patient-oriented attitudes amongst staff. It was suggested that community health projects could be more involved in the training of community health professionals; that training projects could be established to enable professionals to have the opportunity for in-service training and students to be on placement with projects. It was stressed that establishing and formalising links between local communities and professionals - whether it be through curriculum changes, planning structures or the funding of joint training projects - was a slow process that should have more than merely experimental status. It was recognised that there is a need for long-term, mainstream funding to tackle this issue, to turn raised expectations into a permanent reality.

# Challenging from within

In 1978 joint discussions began between Brent Social Services and nursing services within Brent Health District to find ways of improving the delivery of care to people living on the Chalkhill Estate. Chalkhill is a windy, corridor-ridden tower block estate with over 40 per cent one parent families and 60 per cent ethnic minority residents. 5,000 people live on the estate. Specifically the discussions were aimed at avoiding duplication of work and liaising in the delivery of a more efficient service. A joint health and social services team was proposed. The Chalkhill Neighbourhood Project opened in July 1980 with two joint funded social workers, two health visitors (originally attached to the Chalkhill Health Centre) and two community workers.

To begin with the health visitors had considerable difficulty in moving away from the traditional individual surveillance model of health visiting because the health authority would not allow them to give up their case load of 400 clients each. Relationships with health visitors in the primary health care team were strained; it wasn't until the case load was relinquished that the two health visitors were able to develop more constructive and complementary relationships with health centre workers as group workers.

The health visitors have gained much inspiration and support from other neighbourhood project workers. Together with team social workers they are challenging the assumption that social work and health visiting can only operate within a service delivery approach. Their work, most of which has been carried out jointly with other team members, has four different strands. First, responding to the high number of young families on the estate, they have established and continue to support a number of groups which meet in the Neighbourhood Project premises; a post natal group, play course for parents, play group, parenting group (together with a social worker), women's health group, and they have set up a toy library. Second, they have initiated a number of schemes involving staff in the Chalkhill Health Centre; a child health clinic at which they run a structured play session with the family aides and a care attendant scheme for the elderly. Third, they offer their expertise to existing community groups; eg the Asian Forum, Neighbourhood English Classes. Finally, together with Neighbourhood Project Workers they are supporting local people who are trying to increase the provision of resources to the estate. They have put forward a case for extending the availability of ante-natal education and welfare rights information, for expanding the Youth Advisory Service and have been involved in a campaign for a Family Centre on the estate. Due to a change in the political balance on Brent Council this scheme is now in abeyance.

The two health visitors are very enthusiastic about the benefits of working in a community development mode within a multi-disciplinary team, provided the links are maintained with those who supply individual care should it be needed. Benefits include earlier referrals, a broader perspective on people's needs, a co-ordinated approach to work with families, a greater understanding of the professional skills of workers in other disciplines, more efficient resource planning and a more stimulating working environment.

There are problems; although the project is a team in the field, in management terms each discipline is responsible back to its own line management. At this level communication is less than satisfactory and attitudes somewhat rigid. Project members have succeeded in obtaining Health Authority agreement to representation on the project's middle management group, but there is yet no Health Authority representative at senior level, where policy and resource decisions are made. The workers feel Health Authority commitment, specifically health visitor management commitment, falls behind the local authority's. They say: "we believe our posts are experimental and not seen as part of future health provision." A pity.

# Promoting self-confidence through group work

## CHAPTER 5

Group work at the Health in Homerton project, Hackney

# Promoting self confidence through group work

An increased awareness of health needs and an increased understanding of the factors affecting health is of little use to people unless they have the confidence to press for change. The experience of the community health movement is that confidence increases when experience is validated - and that the best place for this to happen is in a group. Alison Watt described what the group process can mean for an individual:

> "The sharing of experiences and knowledge and the discovery by an individual that s/he is not the only person suffering, thinking or experiencing in such a way 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." (16)

Obviously groups fulfil many other needs on the way: they reduce isolation, they can be educative, they give people a chance to help others from their own experience, they are fun. The job of the community health worker is to foster group participation and group awareness - not to lead the group. The community health worker from Stockwell Health Project in South London described the group process in the London Community Health Resource newsletter, Health News, May/June 1984:

> "I think one of the big things community health work has done is to make visible people's experience - affirmation. And to make the links between experience and knowledge - hard and fast resources that people can turn to all sorts of uses. When you begin to appreciate that because of experiences you've gone through you know something, that brings confidence. And as that confidence becomes affirmed by people you're working with and through things you're doing, that leads to further confidence and you can become more assertive. Then you're in a position to negotiate. When you

can negotiate, you can obtain resources, you can gather information, you can organise, you can form a network, you can take action, you can get things done! "

## Breaking boundaries

This workshop looked specifically at the role of groups in a traditional and well-established area of health care: child health and health visiting. Two health visitors, from Family Start, Oldham and Paddington and North Kensington District Health Authority explained how and why they had moved away from working with mothers and their babies on an individual basis and in one case, why they had begun working with completely different groups of people.

The aim of the Family Start project was to reach and assist young families living on the Sholver Estate, Oldham, during the difficult period of transition to parenthood with a view to preventing some of the parenting problems young families experience. The project was connected to Oldham Family Service Unit and staffed by a co-ordinator with a health visiting background, a social worker and a group worker. The project aimed to contact all young families on the estate through its links with the patch-based midwives, health visitors and GP. They interviewed each family that agreed to be interviewed during pregnancy, when the baby was six weeks old and finally at one year. Through the questionnaire families were given the opportunity to define their needs themselves and the project was able to respond by offering information about local services, and by offering individual counselling, a new parents' drop-in, a fathers' group, family play group, post-natal depression group and a food group where parents cooked and shared a meal together. All these groups were set up in response to the problems that emerged in interview: isolation, poor nutrition due to poverty (in 30 per cent of the families interviewed), and lack of information about pregnancy and childbirth which meant a low take-up of services. The interview also provided a data base for evaluation of the project.

The project complemented the work of local health professionals and worked closely with them. However, its success lay in the fact that Family Start workers were not identified by families as belonging to the statutory or professional system (their offices were based in a council house on the estate) and that they worked with groups. Take the food group, for example. The interviews gave an indication of the need (eg nutritional advice); the atmosphere of trust in the food group opened up the depth of the problem, and its communality; and a mutually supportive and practical way of dealing with it was found in the cooking sessions. It was suggested in the workshop that this success raises crucial questions for health professionals about how they present themselves and how they work with people, particularly as in so many ways this project was providing the service that health visiting claims to provide but so frequently fails to deliver.

Oldham Family Start was funded by Urban Aid from 1978-84 and for five of those years was involved in a continual battle for funds. Resistance came from the medical lobby on the DHA who objected to the style of evaluation carried out. The confidence of NHS management in the value of an intensive patch-based project was never fully won. However, Oldham Health Authority has recently appointed its first community health worker thus continuing the approach begun by Family Start in the District.

The Health Visiting and Community Development Project, Paddington and North Kensington Health Authority is based in an inner city district and attempts to look at ways in which health visiting can overcome the division between community health development and traditional health visiting work. Its aims are to examine how a health visitor can work with existing community groups to promote awareness of health issues. It was set up in response to discussions taking place within health visiting about how best to meet its aims - that is the promotion of health and the prevention of ill health. In 1982 the Health Visitors Advisory Group of the RCN commented that

> "In spite of official statements that the function of the health visitor includes monitoring and meeting the health

> needs of the community as a whole and that primary health care involves participation by the community and the mobilisation of community resources, there is surprisingly little use by health visitors of methods of community development."(17)

In Paddington and North Kensington, the initiative for the project emerged from the experience and frustrations of health visitors themselves, who were attempting to develop new methods of working while still carrying full caseloads. This is in contrast to Oldham Family Start, where it was a voluntary organisation which developed the initiative.

Paddington and North Kensington is a densely populated area; the population is mobile, and there are substantial groups of Spanish, Portuguese, Arab and West Indian people as well as above average concentrations of elderly people and young adults. There is high unemployment, considerable poverty, and much of the accommodation is in multi-occupied furnished dwellings, or tower blocks.

A health visitor was funded by the community nursing department in August 1983 to work for 18 months on this project, attached to the local Health Education Department. The steering group comprised representatives from Health Education, Health Visiting management, London Community Health Resource and Community Medicine. The health visitor described her approach to the work thus:

> "In essence my work involved outreach group work and positive health issues. I go out to community organisations and groups and often my services as a Health Visitor either as a resource, as an initiator of discussions, as an organisation organiser of health courses or as a catalyst to look at health issues. I am promoting health as a valid topic to be discussed in any context, not just when we are ill and seeking services."

The level of involvement varies from group to group. She spends a lot of time working with young adults in youth clubs, youth training schemes and community centres. On their request she runs group sessions with them on:

> "how our bodies change in adolescence and our feelings about that, about sexuality, sex, responsibility and contraception. While the mechanics of puberty and sexual reproduction are taught at school, young people crave the opportunity to talk about feelings, ask questions and find out detailed information about local health services linked with these areas. My aim is to spend time with the group so that we get to know each other and have a greater understanding of each other."

She acts as a resource to different women's groups. For example at the 25th Abrilo Centre she has been running a series of health discussions for Portuguese women immigrant workers with the help of an interpreter. The women have made out their own programme including discussions on the difficulties they have with the health service, there being no interpreting service; backache; constipation; losing weight; breast examination; and how to relax. These discussions are held on a Saturday afternoon.

She works in the same way with groups of active elderly people, running discussions on health issues that concern them - backache, medication, eyes, teeth and chiropody.

At the time of the conference, when the project had been running 10 months, the health visitor had been involved with 17 groups. Although her approach is based in community development, constraints of time and the fact that she works with already established groups means that she describes herself as an outreach group worker. Her success in approaching a group and getting its confidence quickly depends on liaison with the group's contact person, who may be a group member or a local youth or community worker. She sees her skill and knowledge as contributing to the process already begun by the group and its community work support.

She has found that being more widely available than the traditional health visitor and making her knowledge available has created tremendous demand for this kind of Health Visitor involvement. Her plans for the remaining months are for working with a range of organisations to start a menopause support group, a women's health course, pensioners' health course and drop-in afternoon in a tower block surgery for parents with small children. She hopes she has created an awareness of alternative ways of working amongst district health professionals in responding to the needs of the community.

# Working with women

> "Women see health as their concern, women are passionately interested in it, and women are the primary users of the health service. The point is that so much of women's lack of well-being (I don't want to say ill health) is rooted in lack of confidence. Women in our various groups are very clear that the health group is where they come for themselves - their inner selves, if you like and where they grow in respect for themselves." (18)

Most community health projects work mostly with women. The problems women have in common are isolation, stress, despair, low self worth and poverty - all of which are exacerbated by society's definition of their primary role as taking responsibility for looking after children and home.

Mansfield Community Health Project employs three community workers who, as part of their work, are helping local women to tackle some of these problems. One of the workers had been involved with a campaigning group for a well women's centre. Women in the group wanted a centre which could treat women as "whole people", rather than the collection of various centres and clinics which they had to attend for different needs. The campaign was not fully successful at the time (although there are now plans for a well women centre at nearby Ollerton), but it was the impetus for the women involved in the original campaigning group to hold a series of health education sessions in the central library and to set up a counselling group called "Concern for Women."

However, the community health worker felt that this campaign, whilst aiming to provide a service for all women, was involving mainly those more articulate, assertive and confident women. She felt a different approach was needed to reach isolated, tired, working class women living in Mansfield's estates. Rather than asking women to come to her she decided to go to them and offer health sessions in a leisure centre on an estate. The first 'course' (1983) proved immensely successful. The women themselves got involved in organising speakers on different topics such as menopause, sex education in schools, yoga, and dental therapy. The failure of a speaker to turn up one afternoon was the turning point for the group. They discovered that amongst themselves they had the expertise to lead discussions on certain topics - one woman in the group ran a series of cooking sessions,getting the group to think about foods, food additives, budgeting, vegetarianism. What started as a series of courses has become a local women's support group in which the community health worker plays a low key role.

When describing their work with women the health visitors attached to the Chalkhill Neighbourhood Project explained the difficulty of reaching lonely women and the delicate balance which must be kept between project workers initiating ideas and carrying them through and encouraging women themselves to get involved. Many women find the project's women's group, parenting group and play group helpful, but many who could use them don't. Obviously health visitors meet all young mothers, but this relationship is usually stamped with inequality and professional/client barriers. Groups must be pitched at such a level that anyone feels she could belong. Once in the group, the process of developing trust and self confidence can begin. It is also seen as important for those women regarded as activists to have a place to come where they can relax, enjoy themselves and encourage other women to develop their skills too. To meet some of these problems the health visitors decided to hold a women's week on Chalkhill estate, with the emphasis on fun. Opportunities for relaxation, sports, health workshops, arts and crafts, and a women's party were amongst those things on offer. From this, different groups have been established, such as a women's health group and a regular information network for women only. Future plans include a young girl's group and regular evening trips to the theatre or cinema.

# Completing the picture of health – who's learning?

Three projects from Newcastle focussed more explicitly on just how they encourage people to feel more confident in themselves and in their opinions of what their health needs are. The three projects, the Riverside Child Health Project in Benwell, the North Kenton Community Health Project and the Walker Health Project form a loose consortium of projects within the Newcastle District, supported by Newcastle CHC's community health information worker. Jointly they produce a magazine, Health Matters, are campaigning for a Well Woman Clinic in the District and are included in the planning process through their contacts with the Community Health Council.

Although all three projects were started and developed in different ways, they share an approach to community development which they call informal learning. That is, each project is regarded as a health education and information project, each group an informal educative group and each intervention an educational intervention, for health professionals as well as local people.

The Riverside Child Health Project was established in 1979 with a team of doctors and health visitors whose aim was to improve the scope and delivery of services for children in the area and to encourage parents to assume "greater responsibility in the care of their children". In 1980 the project's community worker and Director (Social and Community Work) were appointed and the work of the project expanded to involve parents, their views and expertise, more fully. The project now sees its primary aim (the key to its success) as "reducing the distance, in terms of power and understanding, between health professionals and the public". Only in this way, the project asserts, can relevant improvements and changes be made in service provision.

How does the community development approach of the project contribute to mutual learning and thus help break down these barriers?

First: the project works as a team so that community work input is considered as important in meeting project aims as the expertise of the project's medical director. Members of project medical staff are encouraged to be involved informally with ante-natal groups and parent groups in nurseries, clinics and schools. These groups have a fairly conventional programme of learning about things affecting health, but the aim of the group is to help people learn about themselves and their relationships with others - their children, friends - and their doctor. Whilst group members are learning from each other's experience and learning to feel comfortable with health professionals, the latter are learning about the group's experience of the NHS.

Second: the project has weekly lunchtime discussion meetings for local health professionals to which lay people with experience of some of the topics under discussion are invited to speak. Topics include child abuse, asthma, health surveillance, alcohol problems.

Third: in order to get more local people involved in taking responsibility for information sharing the project has run a series of training courses for women wanting to learn more about working with groups. Topics covered include - what is meant by health, the NHS and "who does what when we're ill", assertiveness, women's health needs, what makes a group tick. Subsequent series have looked at how groups can help us understand and support others in their personal and family problems by taking a common situation each week, such as "the doctor says it's my hormones" and sharing experiences about it. Following the first series two local women were paid on a sessional basis to convene their own women's group with back-up from the community health worker. Another woman has been working with a mother's group at Valley View Nursery.

Fourth: the Information Group. This group consists of parents who with the community worker plan and write leaflets, letters and posters about things concerning health - bed wetting, measles, sleeping patterns in babies and young children. Draft leaflets are usually discussed widely before they are finally printed; and then members of the group use the leaflet in discussion with parents in various groups. One group member described the process:

> "We found a lot of data on bedwetting, and after lengthy discussions, consultation with workers at the project and hard work on our part we produced the first leaflet from the Riverside Information Group. We took the leaflet to mothers' meetings at schools, nurseries, mother and toddler groups, women's groups in the area. We used the leaflet both to inform and to promote discussion..... One of the benefits of the leaflet was, I felt, not only the practical advice given, but the opportunity it provided for parents to talk about their feelings - how they coped, and to gain support from sharing with others something they thought was their problem alone."

Fifth: Riverside Project Forum. This local forum is seen as a place where project users can have some input into the planning process; where they can challenge professionals on issues of service provision; and where as users they too can get involved in deciding project priorities. For example there was local dissatisfaction with ante-natal care - with the provision of childcare facilities, clinic waiting times, staff attitudes and the fact that there were not enough patch clinic sessions. Meetings were set up with senior nursing and administrative staff and some changes have been made.

Through these different ways of involving users and professionals together in groups on an equal basis the project feels it has succeeded in increasing the confidence of local people to deal with health matters; helped them increase their knowledge of health, and professionals' knowledge of users' needs; that it has encouraged a better use of the child health service by taking it out to people and making it more flexible - for example, women have begun talking to health visitors about their own health care, not just that of their under fives; and that the understanding of health professionals about what makes an effective practice and how much that depends on user participation has grown enormously.

North Kenton Community Health Project is based on an estate, which was built in the 1950s to rehouse people from Newcastle slum clearance programmes. A problem for the project is that the estate was designed with few places to meet and no identifiable centre so there is little stimulation for community activity. Environmentally, the estate is run down - flats are damp, heating bills enormous, there are few safe play spaces for small children and inadequate services.

One of the aims of the health project is to develop positive attitudes to physical and mental health. Due to the apparent absence of community networks the project decided to begin with issues that concerned people immediately - damp, play provision, income maintenance - and to link these to information work on what positive health is. The work of this project is important particularly because it goes beyond seeing the health service as bearing the main responsibility for the health of communities. Estate residents successfully lobbied the housing department to get safe window locks in all flats to prevent children falling out and are still negotiating on the damp problem. The project has supported residents in a survey of asbestos on the estate and with a group of local mothers has taken up with the Environmental Health Department the issue of dogs fouling the estate. The group has been successful in getting areas fenced off and made safe for toddlers to play free from this health hazard. The project has also been involved in setting up a credit union on the estate so that local people can avoid having to borrow money at excessive interest rates.

All these intitiatives make a major different to the quality of life and mental health on this badly planned, badly resourced estate and as these gains have been made people have begun to tackle issues of service delivery with more confidence. For example, through the project, a doctor and community nurse now work with the Youth Advisory Service doing educational sessions in youth clubs on sex education, relationships and puberty; and a community midwifery service has been established on the estate.

In many ways, by listening to local needs the project has developed in quite a different way and at a different pace from what was originally envisaged. Rather than concentrating on individual problems of low birth weight, poor nutrition and adolescence, as defined by service providers, the project has helped people to take a broader view of health which does not undermine their ability to understand how to look after their children's health, for example, but examines in environmental and income maintenance terms just where the responsibility lies and what precisely would help them to do it better.

The Walker Health Project is based in an area of high unemployment, poor housing and economic depression on the banks of the Tyne. The project sees its groups not only as educational but also as support groups and aims to tap personal resources that people have to offer each other to build up their sense of well being and confidence. The project makes the point that these are resources that professionals themselves cannot provide but should be aware of when planning and setting up a service. When the project opened it ran a course called "Getting Organised" aimed at management committee members. The course provided information on project management, how to run meetings, local resources and decision making in the NHS.

As well as running groups for parents in local schools, supporting a positive health group called "Life in General", and a reading and writing group which teaches literary skills using health matters, the project is involved in a campaign to improve women's sense of well-being. Beginning in the project area, a public meeting was held in January 1983 at which local women expressed interest in the idea of having an opportunity to discuss a wide range of things which affect their well-being - money problems, housing, diet, anxiety, menopause and common ailments. It was decided to establish well women sessions in the project offices - not a service, but an opportunity to share. The project took this one step further by running a training course for well women session helpers. This was aimed at local women and included things like basic counselling skills, practical relaxation methods, depression, menstruation, local services. As the course was held in the evenings, the project provided cash for baby sitters. The aim in using local women was two fold - to boost their self-esteem and to create an atmosphere where other local women would find it easier to talk.

Since then the project has formed links with the CHC, North Kenton and Riverside Projects to campaign for a well woman project in Newcastle. 400 women were surveyed, and the results were written up in an application to Tyne and Wear Council to finance the project. The project will have three full-time workers who will support patch health sessions in Gateshead and Newcastle for both groups and individuals. Each session will be supplemented by a play worker to care for the children. The projects are waiting to see if their application is successful.

## CHAPTER 6

# Developing techniques for evaluating community health work

A group from the West Lambeth Children's Health Club

# Developing techniques for evaluating community health projects

> "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, that it should be built into every community health initiative."

In his speech Evaluating Community Health Initiatives - an Overview Alan Beattie, Head of Department of Health and Welfare Education, University of London Institute of Education, talked in more detail about some of the complex problems facing evaluators in the field of community development in health.

He discussed the applicability and usefulness of the scientific method in evaluating what is essentially a long-term process rather than a discrete 'social experiment'.

> "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, and attempts to set up controlled field trials of a particular intervention to ascertain the outcome in a group of people who receive this intervention, by comparison with groups who do not. (19) A review of evaluation studies in health education (20) showed that while many attempt, few succeed in satisfying the statistical and technical rigours of research design that this approach demands.
>
> 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, (21) there then arise difficulties of statistical interference (22). 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 incidences of mortality or morbidity, may be far removed in time, taking perhaps several years to show up (23). And finally, for many community health programmes, there may be no single and simple 'outcome' measure that can be used as an evaluation criterion." (24)

Despite the obvious inappropriateness of positivism as the basis of an approach to evaluation, many projects are still under pressure to produce controlled measures of outcome. Trying to make such a philosophy fit can be time-consuming and demoralising for a project and yet rejection of the approach can promote a loss of confidence amongst funders and in some cases, curtailment of grant. Oldham Family Start (see page 62) spent considerable time looking at different methods of and subjects for research when they first opened in 1978. They came up with eight options ranging from research into the effects on parenting of loss of own parents to looking at differing attitudes to the hospital ante-natal clinic and take-up of services.

Because project workers were employed to offer a service as well as to conduct research they decided, for pragmatic reasons, to administer a questionnaire to each client about service delivery with the additional aim of collecting information which might give insight into predictive factors affecting parenting. This style of research was never accepted by clinicians or the District Health Authority and so the confidence of NHS management in the value of an intensive patch-based project was never fully won. In 1984 funding was not renewed by Urban Aid and the project closed.

Although some projects now have research workers attached (Mansfield Community Project, Wells Park Project in south London) and there have been independent evaluations of some projects (the Advice and Legal Representation Project at Springfield Hospital, the Newcastle Community Health Projects), on the whole project workers have to carry out evaluation themselves. It seems crucial therefore that evaluation complements ongoing project work, strengthens it and can be carried out as part of day-to-day community work activities using existing skills. Funders do need to be sensitive to this point.

What is needed is a new approach to evaluation which retains enough rigour, yet doesn't swamp the project; which illuminates and is in tune with the underlying values of the project as described in its aims (see page 15). Projects need to begin redefining the principles of evaluation and claiming a methodology to examine and describe their work.

As Alan Beattie implied, it is pointless - and damaging - for projects to shy away from this task. Why? Because it is educative and because projects do have a responsibility towards funders, users and the growth of the movement as a whole.

# Evaluation in practice

In her speech Diane Plamping, now Senior Lecturer in Community Dental Health at London Hospital Medical College, acknowledged that projects fear evaluation, are mystified by it and urgently need to examine their responsibilities in this direction. As an example she describes the logical and yet creative ways in which the Children's Health Club at West Lambeth Community Health Council has been evaluated. Her assertion is that the rigour with which questions are asked and material recorded and analysed along defined themes is no less scientific than an analysis which eschews process and looks solely to outcomes (always merely a part of any activity which includes raising confidence, increasing knowledge and self-help as basic principles) for a judgement on the efficacy of an initiative.

> "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 health knowledge people need is understandable and can also be 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 work. 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

3) 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:

1) Health as a pleasurable experience
2) Perceptions of health
3) Competence and responsibility
4) Social networks

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

1) The limits of medicine

2) Social and political determinants of sickness and health

3) Communication problems between practitioners and their patients

4) The problems which may arise in hierarchical organisations

We concentrated on health education, including promotion, some 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 (25), Kohl (26), Daniels and McGuire (27) 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 sharply 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 the 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 to the group for further discussion.

An example of a critical incident taken from the worker's chronicle on the theme of competence and responsibiity 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 you 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 a 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 commnity 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 CHI's 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 evaluative 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 effectiveness of most common medical practices is insufficient reason for us to practise 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 biased 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 described previously, 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.

Within the basic framework of values and guiding questions, projects have, therefore, a wide range of techniques to draw from: diary keeping, contact and attendance records (who, where from, why, outcome) regular interviews with users, structured assessment after group sessions, analysing critical incidents, compiling case studies, administering questionnaires.

Stage 4: Piecing it together

Alan Beattie stresses that evaluation remains

> "a complex, elusive business akin perhaps to a detective story that requires all clues to be followed up that may lead to the understanding and resolution of a particular case in point."

The information collected should constantly be considered and checked off against the context and practice of the project. It is also important for adequate allowance to be made for the time needed to establish a project, since growth and development are inevitably slow at the outset. This does not mean that a project is failing. Some exposure of its qualitative and personal aspects are also very important and revealing, for each project is as different and as complex as the community in which it is based.

It is crucial to remember that evaluation should above all strengthen and benefit the project and the community in which it is based, as well as inform the funders and policy makers. Since there are different audiences, there should also be different kinds of presentation. Thus the pressure to produce a formal, polished evaluation should not interfere with the project's own needs for the accessible, quickly-produced discussion papers necessary for reflection, and for essentially private use. This is a point to which all with an interest need to be sensitive.

Finally, Alan Beattie suggests that projects should "start evaluation where you can". Many projects will feel that the simple approaches that have begun to be explored in this chapter will be most appropriate to their work. Constraints on resources, time and personnel will further move them in this direction, but even then it will be impossible even to begin without the funding.

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 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 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 to 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." (28)

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 is one of the tools we use to order the chaos of the experiential data we continuously receive. Certainly 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."

## Developing a framework

Following the leads Diane Plamping has given projects and funders we outline a set of guidelines for developing a new framework for evaluation which projects can begin to apply with confidence.

### Stage 1: Assert the importance of philosophy and values

The first step is to clarify the values underlying the work of the project - a step traditionally ignored in evaluation research. These can be translated into statements of intent that will help to determine the direction evaluation may take. For example, in her speech Diane Plamping described how the evaluation group decided to examine the effects of the health club on the children's self confidence, rather than externally defined 'behaviour change'. This decision reflected the group's belief that 'behavioural change' does not necessarily benefit the recipient but that confidence can be increased by giving children control over the health education they give and receive. It also reflected their view that "the health knowledge most people need is understandable and can be communicated by most people, including children."

This philosophy guided their selection of four themes (health as a pleasurable experience, perceptions of health, competence and responsibility, social networks) around which the work of the club and its evaluation were centred. In this way a statement of principles can act as a yardstick for assessing the fit between values and project activities and may also be a guide to making priorities and plans for the future.

Stage 2: Ask a few simple, powerful questions

Having defined the underlying values of the project the next step is to ask a few questions which will break the aims and values of the project down into manageable bits without losing sight of them. For every project the questions will be different in content, style and number. We will examine how the Children's Health Club used this technique in practice and how another project is considering using it.

The Children's Health Club evaluation group refined its broad questions about "What is health education? What do we mean by peer? Can we define beneficial?" into 74 trigger questions aimed at describing the four organisational themes mentioned above. These trigger questions were asked of all the children in taped interviews and used to analyse the club diary. For example, within the theme 'attitudes to competence and responsibility' the children were asked "Who would you like to come to talk to the club? What sort of person? Could you teach without a worker? What do you feel you could do to make the club better? Do you have certain chores to do in the house?" And so on.

By refining the basic questions whilst keeping their internal consistency we can examine specific activities of a project and yet make valid statements about the project as a whole. An example of how this might work is the Waterloo Community Counselling Project's first aim "To promote the mental health of the inhabitants of the Waterloo area." The first question to be asked is "What is good mental health?" In terms of project values this is not merely the absence of mental illness but the ability to assert one's needs, to take control over one's life, to feel an increase in self-confidence.

The next question is "How can the project 'promote' the ability in Waterloo residents to take more control over their lives?" In answer the project may examine the idea of setting up an assertiveness training course; assertiveness training being a technique which helps people to define their own needs and exercise more choice in meeting them. The next step is to discuss how to run the group, and who it should be aimed at based on project knowledge of the area and project values. The questions can then be further refined to:

Does an assertiveness training course -

a) reach those most in need (local working class women in this context)?

b) hold the women's interest?

c) increase the attenders' ability to assess their own wishes and take up issues for themselves?

The project now has three specific points, consistent with its broad aims to monitor and measure:

1) Was the target group reached?

2) What happened in the group?

3) What were the outcomes?

Stage 3: Develop a recording system

In his paper Alan Beattie described several ways in which projects can record and order information:

Monitoring Processes

> "The strategy here is typically to use survey techniques to enumerate attendance at a particular event or uptake of a particular service (29). Further sophistication may be brought in by 'before and after' survey designs, which lead on to time series sampling, trend analysis, and cohort studies (30). 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 (31). Versions of this approach are widely and routinely used in the evaluation of community health programmes.

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.

## Analysing Clients' Perspectives

Another approach to evaluation is to use qualitative and descriptive data, to elicit and/or articulate the reactions of clients to particular social interventions (32). This strategy would typically employ interviews, group discussions and similar means to obtain conversational data, for subsequent analysis and interpretation (33). These techniques 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 (34).

What this approach frequently reveals is the discrepancy and dissonance between the assumptions of the practitioner and those of the client. 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 (35), so that researcher and informant together 'reflect' upon the problem of representing the client's views.

Several features of this approach seem likely to recommend it 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.

## Appraising Institutional Agendas

This approach seeks to identify and map as widely as possible the 'context' - social, cultural, political - within which a particular programme is conducted, and attempts to portray as accurately as possible the displacement effects, the 'impact' of a programme. 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 a 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 kinds 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."

# Conclusion

## CHAPTER 7

# Conclusion

A report which describes such a diversity of ideas and activity is not easy to sum up. But the key points about community health development projects which are given below cannot be ignored by anyone who is seriously concerned about the provision of health care facilities, the promotion of health and the prevention of ill-health.

Summary of key points

1) Community health development projects work to a broad definition of health which considers the whole person whilst looking beyond to an analysis of the physical, social and political influences on health.

2) From this perspective community health development projects can challenge and influence the statutory services - which may include the social, housing, environmental and education services, as well as the Health Service. Projects campaign for services where they are not provided and work to improve services and their delivery where they already exist.

3) Community health development projects receive their mandate for this work from the users of services and by their presence expose the service to the practical reality of local need.

4) Nevertheless a large part of the work of community health development projects is with individuals and groups in society who are left out of resource and service planning. Projects work on building confidence, defining health needs and challenging medical, institutional and racist assumptions.

5) Without this support many individuals would not have had the confidence or knowledge to ask questions of their health professional; nor would groups such as non-English speaking women have pioneered advocacy projects throughout the NHS.

The very existence of community health development projects promises a qualitative and mutually beneficial change in the relationship between the local community and the Health Service, which will become more responsive to locally defined need, more interested in community initiatives, more open to criticism and to change. The freedom from bureaucratic structure and professional constraint which community health development projects enjoy also enables them to cross boundaries and perceive new ways of working, bringing people and organisations together in new relationships which are a pre-requisite for social change and for better health.

# References

1. WATT, Alison - Community Health Initiatives: Clarifying the Complexities within the Community Health Movement. Paper given to conference at King's Fund Centre, June 1984.

2. Ibid.

3. ROSENTHAL, Helen - Neighbourhood Health Projects - Some New Approaches to Health and Community Work in parts of the United Kingdom, Community Development Journal, Vol 18 No 2, 1983.

4. Five Years On, Annual Report of Ormiston Road Centre, Greenwich MIND, 1982.

5. TOWNSEND and DAVIDSON (eds) - Inequalities in Health, The Black Report pp 132-3, Penguin, 1982.

6. Is it just my Age? Report by Pensioners' Link, Brent, July 1984.

7. Ibid.

8. Ibid.

9. TUDOR HART, J. - The Inverse Care Law, Lancet 1, 1971, quoted in Inequalities in Health, The Black Report, op cit.

10. TOWNSEND and DAVIDSON (Eds) 1982, op cit.

11. For example, BROWN, G.W. and HARRIS, I. - Social Origins of Depression: A Study of Psychiatric Disorder in Women, Tavistock, 1978 and FAGIN, L. Unemployment and Health in Families, DHSS mimeo, 1981.

12. OPCS Monitor - Ref DH4 81/4, 6 October 1981.

13. Unemployment, Health and Social Policy, by the Unemployment and Health Study Group, a report of a seminar held in Leeds, 1983. Nuffield Centre for Health Service Studies.

14. Five Years On, Annual Report of Ormiston Road Centre, Greenwich MIND, 1982.

15. Ibid.

16. WATT, Alison, op cit.

17. Thinking about Health Visiting, Health Visitors' Advisory Group of the Royal College of Nursing, para 6:25, 1982.

18. Taken from an interview with Pat Gonsalves, community worker from Stockwell Health Project, published in Health News, newsletter of London Community Health Resource, May/June 1984.

19. For example BARKER, D.J.P. - Evaluation of Preventive Measures (Chapter 6) and ROSE, G. - Epidemiology in Medical Practice, Churchill Livingstone, 1976.

20. GATHERER et al - Is Health Education Effective? Health Education Council, 1979.

21. CAMPBELL, D.T. and STANLEY, J.C. - Experimental and Quasi-Experimental Designs for Research, Rand McNally, 1966.

22. CAMPBELL, D.T. and ERLEBACKER, A. - How regression artifacts in quasi-experimental evaluations can mistakenly make compensatory education look harmful, in HELLWORTH, J. (Ed) - The Disadvantaged Child Vol. III, Brunner Mazel, NY, 1970.

23. MORRIS, J.N. - Uses of Epidemiology, 3rd Edition, Churchill Livingstone, 1975.

24. KNOX, E.G. (Ed) - Epidemiology in Health Care Planning, Oxford University Press, 1979.

25. HOLT, J. - How Children Learn, Penguin, 1970.

26. KOHL, H. - 36 Children, Penguin, 1971.

27. DANIELS, S. and McGUIRE, P. (Eds) - The Painthouse - Words from an East End Gang.

28. PIAGET, J. - Origin of Intelligence in the Child, Penguin, 1979.

29. MOSER, C.A.and KALTON, G. - Survey Methods in Social Investigation, Heinemann, 1971.

30. DOUGLAS, J.W.B. and BLOMFIELD, J.M. - The Reliability of Longitudinal Surveys, Milbank Memorial Fund Quarterly, 1956, 24, 227.

31. BENNETT, A.E. and RITCHIE, K. - Questionnaires in Medicine, Oxford University Press, 1975.

32. BLAXTER, M. (Ed) - The Analysis of Qualitative Data: a Symposium, Sociological Review, 1979, 27, 4.

33. COULTHARD, M. - An Introduction to Discourse Analysis, Longman, 1977.

34. GRAHAM, H. and OAKLEY, A. - Competing Ideologies of Reproduction: medical and maternal perspectives on pregnancy, in ROBERTS H, (Ed) - Women, Health and Reproduction, RKP, 1981.

35. SIMONS, H. - Building a Social Contract: Negotiation and Participation in Condensed Field Research, in NORRIS, N. (Ed) - Safari: Theory in Practice, Centre for Applied Research in Education, University of East Anglia, 1977.

# Appendix I

## PROJECTS MENTIONED IN THE REPORT

Age Concern Lambeth, 1/5 Acre Lane, London SW2. There is one community worker funded initially by Lambeth Inner City Partnership, and now by Lambeth Council.

Asian Community Action Group, 322 Brixton Road, London SW9. The project employs one community health worker, out of a total of six workers. This post is jointly funded by Lambeth Inner City Partnership and West Lambeth Health Authority, until March 1987.

Bereavement Counselling Service, Age Concern Lambeth, 1/5 Acre Lane, London SW2. There are five counsellors and a number of volunteers. The project has been funded by Joint Funding since March 1984.

Bethnal Green Health Project, Oxford House, Derbyshire Street, London E2. Oxford House is a settlement dating back over a hundred years. The project employs one worker, and is funded for three years until June 1985, by the King Edward's Hospital Fund for London, the Inner London Education Authority, and the City Parochial Foundation.

Brent Black Mental Health Project, Harlesden Community Project, 13 Nicholl Road, London NW10. There is a paid co-ordinator for the volunteers. The project has been running since 1982 on a grant of £16,000 from the Greater London Council.

Brent Pensioners' Link, c/o Brent Community Health Council, 16 High Street, London NW10. The project employs two community development/community health workers, and has been funded by Brent local authority since 1979. Re-funding in 1985 is dependent on the outcome of decisions about rate-capping.

Chalkhill Neighbourhood Project, 369 Greenrigg Walk, Chalkhill Estate, Wembley Park, Middlesex. The project was set up in 1980. There are two health visitors based there, two joint-funded social workers and two community workers.

Community Health Initiatives Resource Unit, National Council for Voluntary Organisations, 26 Bedford Square, London WC1. The project employs three full-time workers, and was set up in 1983 with funding from the DHSS, until April 1986.

Family Start Oldham, c/o Rochdale Family Service Unit, 37 St Albans Street, Rochdale. The project was Urban Aid funded from April 1979 to March 1984, when it ended. It employed a co-ordinator (with a health background), a social worker from Oldham local authority, and a group worker and secretary (both part-time).

Greenwich Black Women's Health Project, c/o St Mary's Church Hall, Greenlaw Street, Woolwich, London SE18. The project started in February 1984 with two years' funding from the GLC Women's Committee. In November 1984 the project employed one development worker, one administrator and one co-ordinator full-time; it planned to employ five more full-time workers.

Haringey Link Workers Project, Mountford House, The Green, London N15 4AN. The project was started in April 1984, and employs 10 part-time link workers and one full-time co-ordinator. It is funded by the Manpower Services Commission, and new workers have to be found and trained each year.

Health in Homerton, 282 Banister House, Homerton High Street, London E9. The project was initiated by City and Hackney Community Health Council, and employs two full-time workers, and several sessional workers. It has been funded since 1980 by Inner City Partnership (NHS) funding.

Health Visiting and Community Development Project, c/o Paddington and North Kensington Health Education Unit, Health Education Centre, 287 Harrow Road, London W9. One health visitor was funded by the Community Nursing Unit in 1983 to work for 18 months on this project.

Islington Turkish Women's Health Project, c/o Thornhill Neighbourhood Project, Orkney House, Caledonian Road, London N1. The project started in February 1983, and employs three part-time community development workers. It is part of the Turkish Education Group which is involved in a number of projects in the Turkish community. The health project is funded by Islington Inner City Partnership.

London Community Health Resource, London Voluntary Service Council, 68 Chalton Street, London NW1 1JR. The project has two full-time and two part-time workers. It was set up in 1981 with a grant from the King Edward's Hospital Fund, and now has additional funding from the GLC Women's Committee, until 1986. The Health Education Council has given a grant for one year to cover one and a half of these posts (until August 1985).

Mansfield Community Health Project, 36 Wood Street, Mansfield, Notts. The project was set up in 1982, with funding from the Health Education Council for a community development worker, an action-research worker, and an administrator; and two other community development workers funded by Nottingham Social Services Department.

Maternity Services Liaison Scheme, Brady Centre, Hanbury Street, Spitalfields, London E1. The project employs nine full-time community health workers plus a full-time co-ordinator, and is funded until March 1986 by the GLC Women's Committee and Tower Hamlets Inner Area Programme.

Multi-Ethnic Women's Health Project, City and Hackney Community Health Council, 210 Kingsland Road, London E2. The project was set up by the CHC and Hackney Council for Racial Equality in 1980, with Inner City Partnership (NHS) funding. Funding is secure until 1988, and there are currently three full-time and three part-time posts.

North Kenton Community Health Project, Kirkwood Centre, Kirkwood Drive, North Kenton, Newcastle-upon-Tyne. The project employs two full-time community health workers and a part-time admin worker, and is funded by Inner City Partnership. Funding expires in March 1985, but Newcastle Council has agreed to re-fund the project until 1987 at the same level.

Ormiston Road Centre (Greenwich MIND), 54 Ormiston Road, London SE10 OLN. The centre employs four workers, and was originally funded, starting in 1979, by Docklands Urban Aid. Funding is now from Urban Aid, the GLC Women's Committee and Joint Funding, and should be secure until 1989.

Riverside Child Health Project, Riverside Centre, Benwell Library, Atkinson Road, Benwell, Newcastle upon Tyne 4. Funding for the medical team came from a grant to Newcastle Health Authority from Sainsbury Trust and Inner City Partnership, which ended in 1984. The Project Director (Social and Community Work) is funded by Save the Children Fund until March 1985, with the possibility of a further two years. The project also employs a full-time community health worker, a part-time information worker and an administrative assistant, funded by Newcastle Inner City Partnership for two years from March 1985.

Springfield Hospital Advice and Legal Representation Project, Springfield Hospital, 61 Glenburnie Road, Wandsworth SW17. The project employs two advice workers and one solicitor. It was initially funded for two years by the King Edward's Hospital Fund for London, and is currently funded by the GLC for £45,000 pa.

Stockwell Health Project, Lady Margaret Hall Settlement, 460 Wandsworth Road, London SW8. One community worker has been funded since 1982 by Lambeth Inner City Partnership (via the Health Authority). From 1980-82, funding came from the King Edward's Hospital Fund, and the Special Trustees of St Thomas' Hospital.

Tooting Bec Hospital Citizen's Advice Bureau, Tooting Bec Hospital, Tooting Bec Road, London SW17 8BL. It is part of the Greater London Citizen's Advice Bureau Service, and is funded by the Greater London Council, which has recently approved funding for a second advice worker, until June 1986.

Training in Race and Health, 18 Victoria Park Square, Bethnal Green, London E2 9PF. This national project employs six workers, and was set up by the National Extension College in 1982 with a three year grant from the Health Education Council.

Walker Health Project, The Shop, 6 Redhead Drive, Walker, Newcastle-upon-Tyne. The project employs one community health worker and part-time clerical worker, and is funded by Newcastle Inner City Partnership. Funding expires in March 1985, but Newcastle Council has agreed to re-fund the project until 1987 at the same level.

Waterloo Community Counselling Project, c/o St John's Church, Waterloo Road, London SE1. The project was set up in 1981 with funding from the Special Trustees of St Thomas' Hospital, to cover sessional work by trained counsellors and honoraria for those in training. Because of West Lambeth Health Authority's commitment to a strategy for community mental health, the project is currently negotiating mainstream funding with the District to cover additionally the salary for a link/administration worker.

Waterloo Health Project, c/o Waterloo Action Centre, 14 Baylis Road, London SE1. The project employs two community workers, and is funded 50 per cent Lambeth Inner City Partnership, and 50 per cent Lambeth Council (Social Services) until March 1985.

# Appendix II

## COMMUNITY DEVELOPMENT IN HEALTH: ADDRESSING THE CONFUSIONS

Wednesday, 13th June 1984

King's Fund Centre, 126 Albert Street, London NW1

### PROGRAMME

9.45 Arrive and register

10.00 Chairman's introduction to morning session
**Sir Douglas Black**

10.10 Clarifying the complexities within the community health movement
Alison Watt, Development Officer, Community Health Initiatives Resource Unit

10.30 The need for community development in health
Robert Morris, District Medical Officer, West Lambeth Health Authority

10.50 COFFEE

11.15 A community development approach to race and health
A representative, Training in Health and Race Project

11.35 Evaluating community health initiatives: an overview
Alan Beattie, Head of Department of Health and Welfare, Institute of Education

11.55 Evaluation in Practice
Diane Plamping, Senior Lecturer, Department of Community Dental Health, Camberwell Health Authority

12.15 Discussion

12.45 LUNCH

During the lunch break participants will be able to view videos and displays illustrating the work of some community health projects

2.00 Workshops

There will be a choice of six workshops:

WORKSHOP 1: Breaking Boundaries: Health Visitors involved in Community Initiatives

Joy Courtney SRN, HV, Certificate in Counselling: Rochdale Family Service Unit

Vari Drennan: Health Visitor working with community groups in Paddington and North Kensington HA.

WORKSHOP 2: Informal Learning

Margie Craig: Community Worker, Riverside Child Health Project

Angela Oxberry: Community Worker, North Kenton Community Health Project

Gwyneth Brookes: Community Worker, Walker Health Project

WORKSHOP 3: Linking with and Challenging Statutory Services

Katrina McCormick and Anne Tibbs: Community Workers, Waterloo Health Project

Anita Patel: Community Health Worker, Asian Community Action Group

Hafize Ece: Health Worker, Hackney Multi-Ethnic Women's Health Project

Marie Lewis: Chair, Hackney Multi-Ethnic Women's Health Project; Member, City and Hackney CHC

WORKSHOP 4: Mental Health

Theresa Leo: Advice Worker, Tooting Bec Hospital Citizens' Advice Bureau

Jenny Rogers: Advice Worker, Advice and Legal Representation Project at Springfield Hospital

Wilfred Roach: Chairperson, Brent Black Mental Health Project

Sheila Broderick: Centre Worker, Ormiston Road Centre, Greenwich

Jackie Summers: Counsellor, Waterloo Community Counselling Project

WORKSHOP 5: Pensioners' Health

Caroline Hosking: Development Officer, Age Concern Lambeth

Susan Kerrison: Field Worker, Brent Pensioners' Link

Christine Smith: Community Worker, Bethnal Green Health Project

WORKSHOP 6: <u>Working with Women</u>

Jenny Finch: Community Development Worker,
Mansfield Community Health Project

Gill Dennies and Pat Wickstead: Health
Visitors, Chalkhill Neighbourhood Project

3.30 TEA

3.45 The future of community health initiatives
Discussion chaired by David Towell, Assistant Director, King's Fund Centre

4.15 Chairman's concluding remarks

# Appendix III

## COMMUNITY DEVELOPMENT IN HEALTH: ADDRESSING THE CONFUSIONS

Wednesday 13th June, 1984

### PARTICIPANTS

| | | |
|---|---|---|
| Ms K. ALLEN | | Association of County Councils |
| Dr A. AMOS | Senior Scientific Officer | Hampstead HA |
| Ms J. BAILEY | Director of Nursing Services (Community) | Paddington & N.Kensington HA |
| Mr A. BEATTIE * | Head of Department of Health and Welfare | Institute of Education, London |
| Mrs C.B. BICKNELL | Chairman | Victoria HA |
| Sir Douglas BLACK (Chairman) * | | |
| Dr D. BOOMLA | Chairman | Bexley FPC |
| Ms S. BRODERICK | Worker | Ormiston Road Centre, Greenwich |
| Ms G. BROOKES | Community Worker | Walker Health Project, Newcastle |
| Ms K. BROWN | Student Unit Supervisor | Coventry Social Services |
| Ms J. CHAPLIN | | London Community Health Resource |
| Mr A. CLAYTON | Chairman | Bury HA |
| Mr T. CORBIN | Health Education Officer | Central Nottingham HA |
| Ms J. CORNISH | Health Education Officer | Hammersmith & Fulham HA |
| Mrs B. COTTON | Principal Administrative Assistant | Clwyd HA |
| Ms J. COURTNEY | | Rochdale Family Service Unit |
| Ms M. CRAIG | Community Worker | Riverside Child Health Project, Newcastle |
| Ms G. DENNISS | Health Visitor | Chalkhill Neighbourhood Project, London |
| Dr M. DLUGOLECKA | Specialist in Community Medicine | Dorset HA |
| Dr J.S. DODGE | District Medical Officer | Rugby HA |
| Mrs S. DONOVAN | Nursing Officer, Child Health | Mid Surrey HA |
| Dr S. DOWLING | Lecturer in Community Medicine | University of Bristol |
| Ms V. DRENNAN | Health Visitor | Paddington & N.Kensington HA |
| Mrs H. ECE | Health Worker | Hackney Multi-Ethnic Women's Health Project |
| Mrs J. ELLACOMBE | Secretary | Special Trustees for St Thomas' Hospital |
| Ms R. EVANS | Co-ordinator | The Maternity Alliance |
| Mrs G.B. FENNING | Member | S W Hertfordshire HA |
| Ms J. FINCH | Community Development Worker | Mansfield Community Health Project, Nottingham |
| Mr W.J. FRASER | Administrator and Fellow | King's Fund |
| Mrs J. FULFORD | Director of Nursing Services (Community) | Barking, Havering and Brentwood HA |

| | | |
|---|---|---|
| Mr T. GANG | Principal (Voluntary Work) | DHSS |
| Mrs S. GARGUILO | Member | West Suffolk HA |
| Mr A.E. GAUNT | Unit Administrator (Community) | N. Lincolnshire HA |
| Ms E. GLOVER | | Commission for Racial Equality |
| Ms P. GORDON | Project Officer | King's Fund Centre |
| Dr S. GRIFFITHS | Senior Registrar in Community Medicine | City & Hackney HA |
| Ms L. HADFIELD | Unit Administrator (Community and Family Services) | Hammersmith & Fulham HA |
| Mr M. HARDIE | Director General | International Hospital Federation |
| Mrs M.P. HARRIS | District Health Education Officer | S. Warwickshire & Rugby HAs |
| Mr G. HEAFFORD | Unit Administrator (Community) | North Manchester HA |
| Dr H. HODGE | Health Promotion Coordinator | South Sefton HA |
| Ms J. HUGHES | Project Officer - London | King's Fund Centre |
| Mr P.F. HUNT | Controller | Skinners Guild |
| Mrs K. JOHNSON | Unit Administrator (Community) | South Birmingham HA |
| Mr B. JONES | | Association of Metropolitan Authorities |
| Ms M. KEENE | Health Education Officer - Community | Lewisham & N. Southwark HA |
| Mr D. KENNY | Senior Planning Officer | Gwent HA |
| Dr P.A. KITCHENER | District Medical Officer | Hillingdon HA |
| Ms M. KNIGHT | Administrative Secretary | CHIRU |
| Mr P. KNIGHT | Assistant Director of Social Services | London Borough of Camden |
| Ms T. LEO | Advice Worker | Tooting Bec Hospital Citizens' Advice Bureau |
| Ms M. LEWIS | Chair | Hackney Multi-Ethnic Women's Health Project |
| Mrs J. LYONS | Member | Rochdale HA |
| Mr D. McASEY | Unit Administrator (Community) | Macclesfield HA |
| Ms K. McCORMICK | Community Worker | Waterloo Health Project, London |
| Ms S. MALIK * | | Training in Health and Race |
| Dr B. MARKS | Representative | Royal College of General Practitioners |
| Ms J. MITCHELL | | Greater London Council |
| Ms E. MORGAN | Assistant Director of Nursing Services (Community) | Oxford HA |
| Miss E.D. MORRIS | Community Health Services | Barking, Havering and Brentwood HA |
| Dr R. MORRIS * | District Medical Officer | West Lambeth HA |
| Miss S. MOWAT | Representative | Health Visitors Association |
| | Director of Nursing Services (Community) | Bloomsbury HA |
| Dr N. OLSEN | District Medical Officer | Hampstead HA |
| Mrs J. ORR | Representative | Royal College of Nursing |
| Ms A. OXBERRY | Community Worker | North Kenton Community Health Project, Newcastle |
| Dr T.S. PAINE | Representative | Royal College of General Practitioners |

| | | |
|---|---|---|
| Ms A. PATEL | Community Health Worker | Asian Community Action Group, London |
| Mr J. PEARSON | Secretary | Archbishops Commission on Urban Priority Areas |
| Ms D. PLAMPING * | Senior Lecturer, Dept of Community Dental Health | Camberwell HA |
| Mr C. POLLITT | Senior Lecturer in Government | Open University |
| Mr A. PURKISS | Head of Policy Planning Dept | NCVO |
| Mrs A. RALFE | Assistant Grants Secretary | King Edward's Hospital Fund for London |
| Mr A. RATCLIFFE | Assistant Secretary (Primary Health Care) | DHSS |
| Miss K. RICE | | Tudor Trust |
| Mr S. RICHEY | Education Director | Gulbenkian Foundation |
| Miss M. RIDDOCH | District Nursing Officer | North Sefton HA |
| Dr J. ROBERTS | Senior Lecturer - Health Economics | London School of Hygiene and Tropical Medicine |
| Ms S. RODMELL | Health Education Officer | Hounslow & Spelthorne HA |
| Ms J. ROGERS | Advice Worker | Legal Representation Project, Springfield Hospital |
| Ms H. ROSENTHAL | | London Community Health Resource |
| Mr D.H. RUSSELL | Director of Nursing Services | The Maudsley Hospital |
| Dr D. ST GEORGE | Research Epidemiologist | Victoria HA |
| Dr A. SCOTT-SAMUEL | Specialist in Community Medicine | Liverpool HA |
| Ms M. SCRUGGS | | CHIRU |
| Ms A. SHARDA | Campaign Assistant | DHSS |
| Mrs I. SHARMA | Chairman | Rochdale CHC |
| Dr G.C. SIEGRUHN | District Medical Officer | Redbridge HA |
| Mrs P. SINCLAIR-LEE | Member | Maidstone HA |
| Ms C. SMITH | Community Worker | Bethnal Green Health Project, London |
| Mr G. SMITH | Head of Project Development | NCVO |
| Ms G. SOMERVILLE | | London Community Health Resource |
| Mr P. SOMMERFELD | Director | LVSC |
| Ms J. SPRAY | Senior Health Education Officer | Paddington and North Kensington HA |
| Mr W.H. SPRAY | Grants Secretary | King Edward's Hospital Fund for London |
| Mr P. STONE | Director of Community Services | Newcastle Social Services |
| Ms J. SUMMERS | Counsellor | Waterloo Community Counselling Project, London |
| Dr M. SUTTON | Senior Clinical Medical Officer | Newham HA |
| Mr D. THOMAS | Chief Administrative Nursing Officer | Pembrokeshire HA |
| Mr R. THORNE | District Administrator | Oldham HA |
| Ms J. THORNTON | Liaison Officer - Thames Regions | Health Education Council |

| | | |
|---|---|---|
| Miss M. THWAITES | Professional Officer - HV Education and Training | English National Board for Nursing, Midwifery and Health Visiting |
| Dr D. TOWELL * | Assistant Director | King's Fund Centre |
| Dr P.A. TROOP | Specialist in Community Medicine | Cambridge HA |
| Prof H. WALLER | on sabbatical in London | Luneburg Polytechnic |
| Ms M. WANN | | London Community Health Resource |
| Ms A. WATT * | Development Officer | CHIRU |
| Ms P. WICKSTEAD | Health Visitor | Chalkhill Neighbourhood Project, London |

* Denotes speaker

00 048572 020000