CHCHC

An Experiment in Advocacy

The Hackney Multi Ethnic Women's Health Project

edited by

Jocelyn Cornwell and Pat Gordon

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AN EXPERIMENT IN ADVOCACY:
THE HACKNEY MULTI ETHNIC WOMEN'S HEALTH PROJECT

edited by Jocelyn Cornwell and Pat Gordon

Report of a conference organised by
the King's Fund in collaboration with
City and Hackney Community Health Council
held at the King's Fund Centre on 4th June 1984

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PREFACE

ZOHRA ALI ZUBAIR:

"I have been doing this job for four years, and I would like to talk about my experiences. At first we had difficulty in getting people to accept that we weren't just interpreters. They kept asking us about our qualifications. We felt that we could speak for and help women of our communities through our own experiences. What we do is offer help and support in the clinics. We visit the wards, run groups in hospitals and health centres and visit women at home.

When women come for booking-in, we take their personal and medical history and present it to the medical staff. It saves time, and the information is more accurate. We try and make sure that women's wishes are met. Our biggest problem is shortage of women doctors. A lot of women would like to be seen by a woman doctor, but for our women it is very important because it is in our religion and culture that women are not seen by any man other than their husband. This is the way they have been brought up. They feel guilty and shameful. Some of them go home and ask forgiveness of God for breaking the Law; some put their hands over their face while they are being examined, and some have tears in their eyes. I feel very annoyed; I am by their side and can do nothing to help them. I watch them tremble with fear. I also feel guilty.

Women are very relieved to see us when they come to the clinics. Many of them have a lot of problems. We try to find help for them. If the problem is due to their pregnancy or health, we can always get help and advice. We usually know in advance what question the doctor is going to ask, and can give them information in advance to help them make their decision. For example, if it is likely that a woman will be offered amniocentesis, we talk to them about it and explain what is involved.

Sometimes women are unhappy about the doctor's decisions - for example, an elective caesarian. We explain to the doctor why she does not want it, and in some cases the consultants agree to help them go into labour normally. We also have to tell women when there is something wrong with their baby. It is very difficult for us because we have built a special relationship with them throughout their pregnancy, so we have to prepare ourselves to give the bad news and we continue to give help and support.

We visit the Special Care Baby Unit and get information about the babies and give it to the mothers. We usually go with them on follow-up visits to the Children's Hospital.

We help our women in labour wards; we give them constant support and it helps to make the delivery much easier. I'd like to give an example. Once I was with a mother whose baby had the cord around its neck. She was anxious to get over the delivery. She ignored the midwife who was telling her to stop pushing. I explained to her what the position of the baby was. She immediately realised the danger and became cautious. I believe it would have been difficult for the midwife to convince her.

We often get pressurised with their social problems, like housing, financial and marital. We try to refer them to other organisations, but sometimes it is not possible, so we find ourselves filling in forms for them, writing letters, making phone calls on their behalf, and sometimes accompanying them to various offices like the Citizens' Advice Bureau, Centerprise (a local community centre) and the DHSS to make sure they get their rights.

If we have very difficult problems we discuss them in our weekly sessions, and sometimes we take them to the steering group. For years I have been trying to get something done about access to women doctors. Sometimes I get very fed up. I try to make arrangements for women to be seen by a woman doctor and then she brings male students in with her, and some of them don't like it when we ask them to leave. But I try to make sure women get what they want and I know that it is better when I am there, and it makes me feel happy".

Photo: Roger Reid

INTRODUCTION

The voice in the Preface is the voice of Zohra Ali Zubair, one of the workers employed on the Multi-Ethnic Women's Health Project in Hackney. The Project has been running successfully for four years, and the main purpose of the conference held at the King's Fund and reported here, was to respond to the very large number of enquiries about the Project which City and Hackney Community Health Council receives and to the widespread interest it arouses in health workers and community groups who hear about it.

To say that the Project is successful is not to say that it has been without difficulty or that it is trouble free. One of the aims of the conference was to make the experience gained in the workings of the Project accessible to other people. In particular, those people interested in setting up similar ventures in other parts of the country would have the opportunity to find out about the problems, the tensions and conflicts of interest, as well as the successes.

The notes on the background included here provide a brief introduction to the Project. Much more useful is the paper in the first part of this report, in which Fedelma Winkler sets out the principles and politics which gave life to the Project and have continued to shape it. Fedelma Winkler is Secretary to City and Hackney Community Health Council and has been involved in the Project from the beginning.

The second part of the report takes up 4 themes in the work of the Project which formed the basis of the conference workshops:

Racism in the health service

The principle of advocacy

Relations between lay and professional health workers

Management of the project

The discussion of each of the themes draws on material from papers presented at the morning session and notes taken in the discussions in the afternoon workshops.

In the third part of the report a medical perspective is given by Neville Wathen, Consultant Obstetrician and Gynaecologist and the Project is put into its district context by Sian Griffiths, Community Physician. Both doctors work in City and Hackney District.

NOTES ON THE BACKGROUND TO THE HACKNEY MULTI ETHNIC WOMEN'S HEALTH PROJECT

This is a small project funded by Inner City Partnership monies to provide a health advocacy and health advisory service for non-english speaking women in Hackney during pregnancy, childbirth and to women with new babies. It is administered by the City and Hackney Community Health Council and can be described as an extension of the CHC's role to the non-english speaking community. It is managed by a steering committee representative of community organisations and health service workers.

Started in 1980

Aims: To improve access to the health service to non-english speaking women during pregnancy, childbirth and in the post-natal period.

To help women understand the choices open to them so that they can make informed decisions about their own health.

To advise the health authority on policy and practice with regards to the needs of non-english speaking women.

To help and encourage health service staff in providing a service to this high risk group.

Work

Employs women from the relevant communities to speak for the women in the maternity unit, to run health support groups in hospital and community, to visit women at home and to advise the health authority on policy.

Selection of Staff

Staff chosen for commitment and experience rather than formal qualifications.

Training

Emphasis on support and facilities for providing information as needs arise rather than formal training as such.

Funds

Provided by Inner City Partnership monies through District Health Authority's Partnership programme - £20,000 year one, £28.500 in year three (83/84).

Staff

5 workers - all part-time.

Turkish speaking worker	-	Hafize Ece
Urdu speaking worker	-	Zohra Ali Zubair
Gujarati speaking worker	-	Mariam Achhala
Bengali speaking worker	-	Shameem Habibullah
Bengali speaking worker	-	Monowara Talukder

Funds are also available for the employment of translators to cover languages not covered by the workers.

Base

Office in the maternity unit with telephone extension. Each worker carries a bleep. One day a week in CHC office.

Management

Day-to-day management - CHC secretary

Policy and support - steering group made up of community representatives and health service staff. Meets 6-weekly.

Overall management - management committee representatives from Community Health Council, Hackney Commission for Racial Equality and District Health Authority. Meets infrequently.

Workers contract of employment administered by DHA. Workers on same scale as CHC Assistant Secretary.

Future

Funds have just been doubled to extend the Project into the community to work with children.

A co-ordinator will be appointed.

The Project will remain attached to the CHC.

Multi Ethnic Women's Health Project,
City & Hackney Community Health Council,
210, Kingsland Road,
London, E2 8EB.

Tel.: 739 6308

Chair: Marie Lewis

Secretary: Fedelma Winkler

Photo: Roger Reid

FROM IDEAS TO PRACTICE: INTERPRETING TO ADVOCACY

Fedelma Winkler, Secretary, City and Hackney Community Health Council

> "One of the main difficulties in communicating is not the physical barrier of different languages but the more fundamental need for immigrants of all nationalities to understand the roles of the various authorities and their employees. Difficulties arise with customs, especially with the Muslim and strict Jewish faith".

It would be interesting to know how many people reading the above statement agree with its sentiments and how many are ready to challenge it. The emphasis on the needs of the organisation is not unique to the NHS or to the City and Hackney Health District to whom this quote was attributed in a publication reviewing health services for Asians put out by Wandsworth Council for Community Relations in 1978. Organisations frequently concentrate on their own needs and not those of users.

The Multi Ethnic Women's Health Project starts with the perspective of the user and seeks ways of meeting her problems. It may be that as a consequence the organisation has to change or staff attitudes have to be looked at. In this paper I shall concentrate on the ideas that led us to set up this project and describe the essential features which have helped us turn those ideas into reality.

The ideas behind the Project

In the late 1970s, teachers of english as a second language began taking classes in the maternity unit, and as so often happens, as outsiders their observations of what was going on were more acute than those of people whose senses had been dulled by repeated exposure. The teachers brought their concern to the Community Health Council, where a discussion ensued about the extent to which the problems faced by Asian women would be met by general improvements in the ante-natal clinic. Many of the problems were ones with which we are all familiar and which have been documented in every survey of ante-natal clinics in the past ten years - impersonalised care, long waiting times and crowded clinics. For non-english speaking women there were the additional problems of racism and being unable to communicate effectively with carers. The hospital too had problems, problems which are usually referred to in the language of obstetrics as 'poor compliance' - late booking, non-attendance and a confused naming system. Indeed, one of the official explanations for crowded ante-natal clinics was that Asians were said to bring their families with them.

The early discussions about whether we should improve the service for everyone or whether there should be a special service for Asian patients have continued to influence the Project but now the assumptions on which those discussions are based have been turned right around. Now if a non-english speaking woman has a problem the question we ask is, to what extent is this also a problem for english-speaking women?

The CHC working party decided that there was no need for further research to refine our understanding of the problem. What we had to do was to come up with ways of doing something about it. Having identified a gap in a service, CHCs are often good at campaigning to have something done about it. Our options seemed to be either to campaign for an interpreting service, or for the employment of health workers in the maternity unit who could speak the necessary languages, or for the appointment of an organiser to draw up a panel of volunteer interpreters. For a variety of reasons, some negative, but in particular because we had a positive desire to do something different, we rejected all of them.

There is no doubt that many interpreters do a valued and difficult job, but there are structural weaknesses in their position which make it easy for them to end up on the side of the professional, rather than that of the person for whom they are interpreting. If they don't, it is often at their own expense. Nor is it realistic to expect to employ staff from the communities of the respective patient groups.

Our motivation to try something different came from different sources but in particular from (a) the ideas and information coming from community health projects in Third World countries where local people are employed to do tasks previously done only by health professionals with formal training, and (b) the Patient Advocacy Schemes in the United States.

The community supportive model

David Werner has provided a useful typology which divides community health projects into those which are 'community supportive', as against ones which are 'community oppressive'*. In his terms, the usual way interpreting schemes work places them as community oppressive and not community supportive. His model has been developed from projects in Central and South America but the principles are no less applicable to our situation. The features of community supportive schemes are:

1) accountability to the community rather than the health professionals working in it

2) share knowledge with people rather than guard it from them, as is more typical of professional health workers

3) workers chosen for their commitment and concern for social justice and not for their formal qualifications

4) workers share as many characteristics as possible with the people for whom they work

5) workers' training is flexible, informal and designed to meet the specific needs of the community and the situation in which they work

6) the project offers a practical service

* Werner, D. The village health workers: lackey or liberator? Prepared for IHF Congress, sessions on health auxilliaries and the health team, Tokyo, Japan. 22-27 May, 1977.

Werner's ideas influenced our thinking about the Project and its management and about the selection and training of the workers. Our idea was to draw up a plan which would meet his criteria for a community supportive scheme.

We proposed that the workers employed by the Project should be selected for their experience - i.e. they would share as many characteristics as possible with the non-english speaking women using the maternity service,for their personal characteristics - i.e. for their commitment to their community and to the work - and they would not be directly accountable to anybody in the NHS management.

The second source of our ideas was the Patient Advocacy Schemes in North America where three quarters of the large hospitals employ advocates or representatives to speak for patients and help them through the medical maze. It was partly these schemes in America, set up in response to the criticism of lack of user/community involvement in health care, which provided the model for CHCs in Britain, and the Royal Commission on the NHS suggested that CHCs might extend their role further in this direction. In fact there are many similarities in the work of the Multi Ethnic Project workers and patient advocates.

Hindsight makes the way in which the Project developed from these ideas seem much clearer than it did at the time. As it was, City and Hackney Community Health Council, in association with Hackney Council for Racial Equality and with the support of Area Health Authority officers, applied for funds to improve the access of non-english speaking women to the health service and to improve the information available to them for making choices and decisions about their own health and that of their family. To do this, we proposed employing women with experiential knowledge of pregnancy and child-rearing and language skills who shared as many characteristics as possible with the women in the maternity unit whom they were committed to help.

Early difficulties

The first, and perhaps the most traumatic time was the initial stage of establishing a steering group. In trying to change from a working party into a steering group, we started by seeking to involve a wide range of community groups. The disputes which arose were over who should select and who should control the staff. In retrospect, we can see that the arguments benefitted the Project; as a result it was decided that

(a) the Project should become an all- women project;

(b) the steering group should be responsible for all appointments;

(c) the majority on the panel making the appointments should be from the ethnic community groups.

All this delayed the formal setting up of the steering group. The CHC agreed that its staff would take over the day-to-day management and this has meant that the Project has taken on more of the characteristics of the CHC than originally planned. It is closely tied to the NHS structure without being part of it; it has extended the role of the CHC into the non-english speaking communities; and it has also extended the CHC's role into representing individuals in hospital.

Right from the beginning the project workers did interpreting work in the maternity unit. They also insisted that although they were not working for the hospital, they were health workers. This caused problems with hospital staff, who did not know where to fit them into the hospital hierarchy and could not accept them as health workers since they had no formal training. Experiential knowledge, the ability to do the job and capacity in language are not highly valued in our society.

The other major problem the project workers faced was that racism which might previously have been covert now came out into the open.
Staff - particularly white ancillary staff and some Caribbeans - resented what they saw as special treatment for one group.

Most organisations find it extremely difficult to accept new roles and there was no reason to suppose that the maternity unit would be any different. Here was a situation in which new workers were coming in from the outside, standing up for a group of very vulnerable women, asking questions and challenging assumptions held about those women and articulating their wishes. The fact that the workers were accepted with relative ease, is a tribute to the support they received from senior NHS staff and to their own personal skills.

The essential features of the Project

The Project has now been running for four years. Once established, good projects are never static and a description can never be more than a snapshot, but one can, I think, identify the features which make it work, as follows:

a) the nature and structure of the Steering Group

b) the decision to select workers for their personal characteristics and invest in support rather than conventional training

c) the emphasis on advocacy

d) the independence of the Project from the NHS hierarchy whilst being closely associated with it.

a) The steering group

The structure of the steering group is very important. It brings together community representatives and health service staff from different parts of the hierarchy. It provides a forum where major issues relevant to the Project and to the health of ethnic minorities can be discussed. It provides valuable support and guidance for the workers.

There is enormous value in bringing together two distinct groups - representatives from community organisations and health service staff - who would not normally sit down together and discuss issues. Those of us with feet in both camps often despair about bridging the gaps between the community and health services. When the steering group began meeting there was, and still is from time to time, aggression, conflict, defensiveness and lack of understanding, but over time the atmosphere has changed. It is not easy for representatives from community groups baffled by the bureaucracies of the NHS to sit down and discuss complex issues with NHS staff, particularly when they have no previous experience. Similarly, it has obviously been difficult for NHS staff to have the services they provide discussed critically in an open meeting.

There are not many opportunities where this can be done, and this aspect of the Project has had considerable spin-offs for the CHC and, I hope, for the health service and the community groups.

The issues brought to the steering group come from different sources, but most often from the workers. Initially there were day-to-day problems which proved difficult for the individual worker to handle. Through the steering group a system has now been worked out whereby if a problem occurs in the hospital, the worker can go straight to a senior member of staff who will undertake to sort it out there and then. This simple procedure has worked for the day-to-day crises, but throughout the four years the two major areas of concern have been racism and access to women doctors.

In presenting racism as an issue we are not in any way suggesting that the Unit where the workers are based is more or less racist than other institutions. What we are interested in is what can be done about it. The contribution of the steering group is that racism has been raised as an issue in the hospital and discussed. The steering group has supported the workers and helped them to challenge racism. It has made its own attempts at challenging the blanket stereotyping statements which are made and which are, in essence, racist. The steering group will not, for example, respond to requests for information on 'what Muslims want' or 'what Asians eat', on the grounds that all religious and cultural groups have their own practices and customs which must be respected and which vary from region to region, between classes and in degrees of religious orthodoxy.

We have tried at all times to put the emphasis on respect for the individual's wishes and to stress that individuals must be asked about their wishes and the system must be flexible enough to accommodate them. The workers' job is to represent the patient's wishes, whilst the task of the steering group is to push for flexibility in the system.

The second major area of concern is the need for women doctors. The steering group has developed a policy that, where possible, women will be seen by women doctors or, where appropriate, by a midwife. Nevertheless, the problems remain of insufficient female doctors and resentment on the part of doctors of both sexes.

We would like to see structural changes made to improve the situation. The CHC is pressing the health authority to implement an equal opportunities policy on race and sex. The CHC has emphasised continuously on many platforms the need to take into account the desires of a substantial proportion of users when medical appointments are being made. In our view this would be helped by the implementation of an Equal Opportunities Policy.

Another issue which has concerned the steering group is food. Again we have tried a holistic approach, stressing to the nutrition working party that bread made with vegetable fat is not only acceptable to everybody, it is said to be more healthy. If the kitchen were to be converted to a healthy food kitchen, the addition of pulses, yoghurt, nuts, potatoes and vegetable dishes cooked without bacon bits would not only improve hospital food for everyone, it would make it more acceptable to the non-english speaking women.

Other issues raised by the Project include the appropriateness of selecting Asian babies for BCG at birth, ethnic record keeping, the use of passports for purposes of identification, customs surrounding death in hospital and particularly post mortems, the need for health promotion and health education, breaking of bad news and the boundaries of the Project. This last, in the early days, was one of the major areas in which we experienced difficulties. The scale of the problems (social, financial and medical) faced by individuals and families, and the complexity and diversity of those problems meant that the workers had to be helped to see that they were not superhuman and could not prevent, let alone solve, all the problems. Other agencies and sources of help had to be found. The steering group was able to play an important supportive part in this.

b) Support and training of the health workers

The workers' training has been different from that of most health workers. The emphasis has been on providing a structure which would meet their needs and support them. In the beginning we had little idea of how to organise the training, and the three hours set aside each week to read, write and learn were used for letting off steam. The time was spent seeking solutions to the week's troubles, finding sources of help for the problems they were encountering, gathering information and thinking about what was needed.

Given the diffuse nature of the work and the novelty and stressfulness of it, this emphasis on learning as needs arose was one of the most beneficial decisions we made. Other facilities for learning were provided. The senior midwifery tutor organised a basic midwifery course for the Project workers and other community workers were invited to take part. The course was valuable, particularly for the opportunity it gave to discuss and contrast taught procedures with observed practices. Other sessions were arranged as the need arose. For example, as a result of tensions between individual members of the group there were sessions with a group leader on working together. Other sessions were led by a bereavement counsellor, to help the workers deal with the heavy emotional demands of breaking bad news.

The emphasis throughout has been on reinforcing the workers' experiential knowledge, and not replacing it. Much of the learning takes place in the course of the work itself. Two of the health workers have been doing the job for four years and one for three years, and are now familiar with the range of responses to be expected from NHS staff. As their knowledge and experience has developed they acquire their own yardsticks by which to evaluate the care and information given to them.

c) Advocacy

In the United States, patient advocates are employed to speak for the whole patient and are able to cross departmental boundaries, seeking information and solving problems. Their brief is to tackle unusual situations, to maintain and represent the perspective of the patient through all departments and, where necessary, to work to reform existing procedures. In American literature they are usually described as 'humanising the services' for the patient. This - with the added task of interpreting - is very much what the health workers employed on the Multi Ethnic Women's Health Project are doing.

After every talk about the work of the Project, women invariably comment on how they wish there had been somebody in the system like that when they had their babies. One of the aims of the conference is to explore the question of whether the advocacy model should be extended to other groups of patients or to patients in general. In this instance it seems non-english speaking women are getting a service many other women would like.

There is another sense in which advocacy is important, namely, that it makes the workers' role manageable and meaningful. Much of their day-to-day work is acting as brokers between two cultures - the culture and needs of the hospital and the culture and needs of the women. Conflicts of interest do arise and difficult decisions have to be taken. The principle of advocacy provides clear guidelines. The workers are there to provide the women with information on which the women can make their own decisions; they speak for the women, not the hospital.

d) The relationship of the Project to the NHS

I want to stress the importance of the fact that the Project is outside the management structure of the NHS but closely attached to it. The position mirrors that of the CHC itself. In many ways CHCs are in a uniquely advantageous position for developing this type of project since they themselves are part of the NHS without being incorporated into the management structure. This position allows the workers to speak for the women; it encourages them to identify with the women and, to assist that process, they do not wear uniforms. Being close to the system they can offer their services to women without waiting to be asked; they can build up stores of knowledge which directly benefit the women and can make that knowledge available at a time when it is most needed. Most importantly, it gives the workers and the Project as a whole a mechanism whereby they can seek to make policy changes and to change peoples' behaviour even if it is not always possible to change attitudes.

This closeness to the NHS has another important aspect, which is that the Project has benefitted from the goodwill and cooperation of large numbers of people in the NHS who continue to support us in our plans to expand over the next five years. We have tried to be a community supportive project. We feel that we have gone some way towards achieving that aim and, in the process, we have helped to make childbirth a less traumatic experience for some women and have begun to humanise the service.

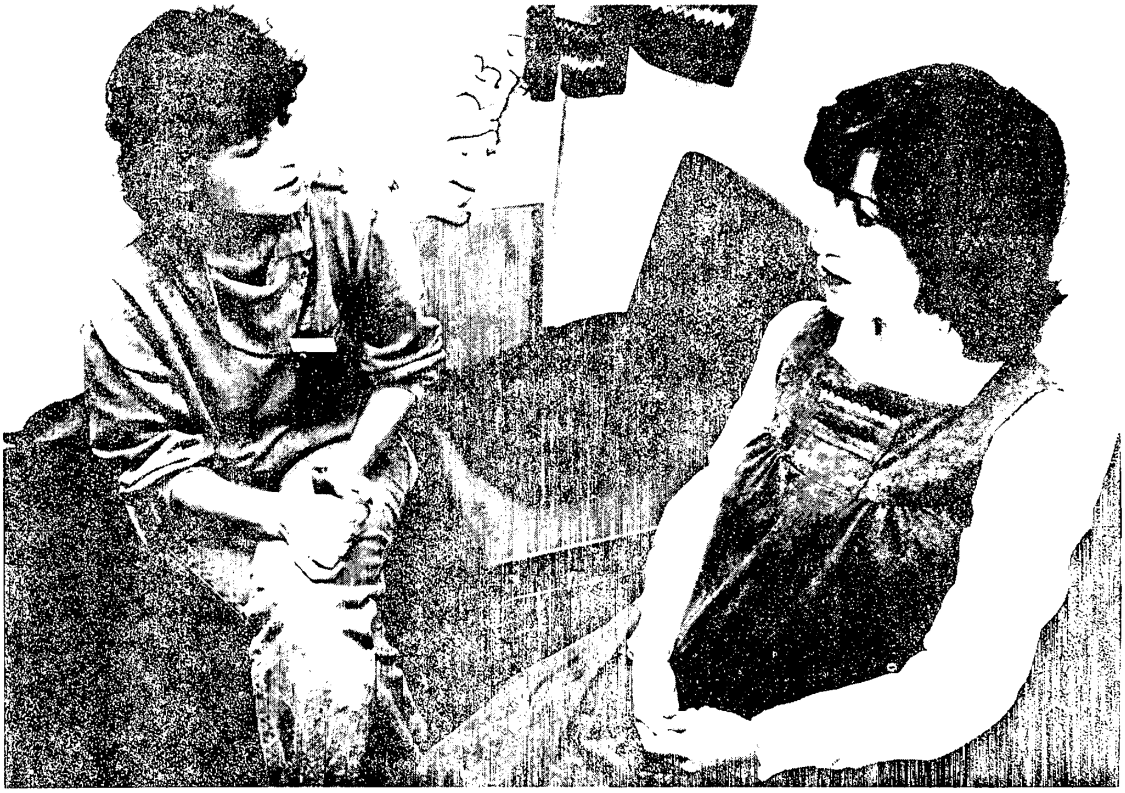

Photo Mike Abrahams / Networks

WORKSHOP THEMES

RACISM IN THE HEALTH SERVICE

Chaired by Colin Franklin and Hafize Ece

The work of the Multi Ethnic Women's Health Project has to be looked at in the context of racism in the National Health Service if it is to be fully understood. Fedelma Winkler points out that the advocacy service provided would be of benefit to most patients but is only available to non-english speaking patients. With limited resources the Project has chosen to speak only for non-english speaking black and ethnic minority women on the grounds that their need for advocates to defend their interests as patients is greater than that of other women.

The position the Multi Ethnic Women's Health Project takes is that *in itself*, language ought not to be a problem, but that, in the context of the health service, black and ethnic minority patients are especially vulnerable and the fact of not speaking english makes the usual problems patients experience (of feeling powerless in relation to the professionals, finding it difficult to ask questions, worrying about what is going to happen etc.), far worse.

The Project has been accused of stirring up racial feeling in the health service in Hackney and of making trouble where previously there was none. But experience in the field of race relations suggests this is a standard complaint whenever something positive is done for ethnic minorities. Often, as in this case, people prefer to believe that the Project has caused trouble rather than accept that what it has done is upset the existing power relations and bring to the surface conflicts which had previously been camouflaged and prejudices which had long been hidden. Certainly this has been the experience of the Project in Hackney because it has made racism in the health service a focus for attention and in the process people have become (often uncomfortably) aware of the many ways in which black and ethnic minority people are discriminated against as patients and as workers.

This report of the workshop on racism in the health service treats black and ethnic minority peoples' experience as patients and as workers as separate issues, but it is hoped that it will be apparent that these two aspects of racism are closely linked. It begins with the treatment of black and ethnic minority patients in NHS hospitals. The fact that most of the examples are taken from the Mothers' Hospital in Hackney is not intended to suggest that there is more racism there than elsewhere. On the contrary, the contributions from people attending the conference from other parts of the country indicate that the Mothers' Hospital is not at all unusual and that the level of racism at the Mothers' is probably typical of the health service more generally.

The second part of the discussion concentrates on racial discrimination in employment and how to combat it.

It may be useful to begin with the definition of racism provided by Colin Franklin, general practitioner and President of the Hackney Commission for Racial Equality, who chaired the workshop on racism. He said racism is "a belief which is translated into action based on the idea that one race is necessarily superior to another race by virtue of something in-born or innate", and that "from that belief stems all the attitudes and behaviours towards different races".

The most fundamental and the most common way in which one sees racism at work in the treatment of patients in the health service is that they are made to feel that they are of no account. This is accomplished by staff in a variety of ways ranging from the example Zohra Ali Zubair gave in the preface of male students being brought in to see patients who have especially asked to be seen only by a female doctor, to a GP's negligence of an Asian patient described below (page 22). The health workers from the Project told of nurses complaining that Bengali women smell (of curry) and saying it is offensive for other patients to have to be in the same room with them; nurses making up their own (English) names for the babies of non-english speaking women; clinic receptionists ordering patients to bring their passports with them to outpatient clinics; patients from ethnic minorities being segregated from other patients. One story (from Bradford this time) was of a hospital purporting to make concessions to patients who are vegetarian, but continuing to use meat fats to cook their food and simply ordering the meat to be scraped from the plates before serving.

When Colin Franklin defined racism, he distinguished it from racial prejudice on the grounds that racism is backed up by institutional or organised power, whereas prejudice is individual. The distinction aroused particular comment in the workshop when Hafize Ece, one of the Project workers, said that Afro-Caribbean nurses at the Mothers' Hospital had been involved in some of the mistreatment of non-english speaking patients. The question arose "Can a black nurse be racist ?" According to Colin Franklin's definition black nurses may be prejudiced but they are not racist, and some participants in the workshop, endorsing this, said it is not possible for black or ethnic minority people to be racist because they lack power. Others, however, disagreed and felt that racism can be - and very often is a feature of relations between different ethnic groups, with examples of Afro-Caribbean prejudice against Asians; Jewish prejudice against non-Jews; Muslims against Hindus.

How does the Multi Ethnic Women's Health Project deal with discrimination and prejudice against individual black and ethnic minority patients ?

If the health workers feel that something which occurs in the hospital or in the community is racist, (see Mariam Achhala's story page 22 below) they report it at their weekly meeting (normally attended by the Community Health Council Secretary, a member of staff from the hospital or community health service and a representative from the community) or to the steering group. From there the matter goes to the appropriate senior member of staff in the NHS who usually sees the worker(s) involved and may take disciplinary action. Experience on the Project has shown that the best and most effective way of dealing with individual cases is by going straight to the officers in charge of the people responsible. The cooperation of senior medical and nursing staff on the steering group has proved invaluable in this respect.

The health workers also hold their own meetings with staff and feel that this has been a positive step in changing the attitudes of Afro-Caribbean nurses in particular. The hospital staff with whom there have been the most difficulties are the receptionists and clerical staff. This may be related to the fact that within the staff hierarchy these workers are relatively powerless and may therefore be inclined to make sure that the people over whom they do exercise some power - the patients - feel inferior.

The difficulties the project workers have had with receptionists and clerks is one example of the way in which racist attitudes and behaviour towards patients is connected to NHS staffing policy. During the workshop people gave accounts of their own experience of being discriminated against as workers, bringing to life the meagre empirical data available on the employment of black and ethnic minority people in the health service. Colin Franklin told how as a houseman applying for jobs in surgery, he was advised by his chief, "You can apply if you like, but you haven't got a chance of getting it". The chief didn't say why and didn't have to, both of them knew it was because Colin Franklin is black. There are very few black and ethnic minority doctors in senior medical posts in this country. Those who are appointed are concentrated in the unpopular specialties - geriatric medicine and psychiatry.

In nursing, black and ethnic minority nurses are more often SEN than SRN qualified (i.e. their qualification is lower). There are very few black nurses in teaching hospitals (centres of prestige in nursing as much as in medicine); black nurses find it harder to get promoted and the areas in which they are promoted are the unpopular ones. One black nurse told how after attending a specialist course in theatre nursing, she was the only student on the course not to be awarded the certificate of qualification. The tutor in charge of the course suggested she would be better placed at home, looking after her husband and children. Another nurse commented on the racial stereotypes which determine where nurses are placed. Oriental nurses are directed into operating theatres and intensive care ("they're good with their hands, but cold and unfeeling"), whilst the more popular specialties, notably paediatrics, are reserved for white nurses.

The numbers of black and ethnic minority paramedical staff are very low. There are, for example, few black ambulance men and only 3-4% of NHS clerical workers from the ethnic minorities. But in domestic work black and ethnic minority workers make up 60% of all kitchen, laundry and cleaning staff.

Having established the way in which racism affects the employment of black and ethnic minority people, the workshop turned to ways of combatting it. At the end, the discussions which took place were condensed into three main proposals:

1. positive action on employment of black and ethnic minority people in the NHS

2. the development of professional codes of practice relating to equal opportunities for black and ethnic minority people

3. racism awareness courses in the health service and the appointment by health authorities of race relations advisors who would be in close touch with local community relations councils.

It was felt that none of these steps, taken individually, would be enough, but that taken together they would make inroads into institutional racism in the health service.

1. Positive action. Positive action does not, as people often assume it does, mean appointing a person who is unsuited to the job simply because she comes from an ethnic minority. It means trying wherever possible to take positive steps in the direction of appointing ethnic minority people, recognising that this has to go hand in hand with a commitment to training. It is too easy to fall back on the excuse that black and ethnic minority applicants do not possess the necessary qualifications which is tantamount to saying that nothing can be done in the field of employment to overcome racial disadvantage in the educational system.

North American experience of positive action has shown that in order for policies to work, they must:

(a) be clearly formulated leaving no room for ambiguity or misinterpretation;

(b) be understood by everyone, from the lowest grade of employee to senior managers;

(c) make provision for the policy to be monitored and evaluated by outsiders;

(d) include a well-publicised complaints machinery.

Whilst the workshop as a whole accepted the need for positive action by the health service, there were two aspects of the policy which raised considerable comment. The first was the anxiety voiced by a female worker and upheld by others that people appointed as a result of such a policy could find themselves the victims of harassment by other NHS employees. If this were to happen, it was felt that they would be unlikely to receive much support from the trade unions. The trade unions were criticised for failing to promote equal opportunities for black and ethnic minority people in the health service and for failing to combat racism in their own organisations.

How best to monitor a policy of positive action raised the subject of 'ethnic monitoring' - whether or not black and ethnic minority workers should be counted. Some members of the workshop had strong feelings against ethnic monitoring and saw this as discriminatory in itself. It was agreed however that ethnic monitoring is an unpleasant but necessary evil, and that it is important to amass statistical data which will show whether or not equal opportunity is a reality in the health service.

2. Professional codes of practice. It is not easy to discern where power lies in the NHS. In other highly bureaucratised organisations it is usually possible to identify the key positions or committees that exert power, but in the NHS the formal structure of the bureaucracy often disguises the much more influential informal structures dominated by the medical profession. In view of the pride the health professions take in regulating their own affairs, it was felt that one of the most effective ways of implementing positive action might be via professional codes of practice. These could be implemented at local level by district health authorities, local professional committees, family practitioner committees etc. and could be monitored by community health councils.

3. Racism awareness training and the appointment of race relations advisors. The workshop recognised a need for racism awareness training for NHS staff and proposed that it should be available as part of the training programme for new employees and to already qualified NHS workers. The appointment of a race relations advisor in each health authority was also recommended. Such posts should be established in close cooperation with local race relations and ethnic minority organisations in the community so that the worker did not become isolated in the NHS.

In the preface, Zohra Ali Zubhair comments on the importance that she and the other health workers attach to their efforts to make sure that women who do not want to be seen by a male doctor will always be seen by a female doctor. This issue of access to women doctors is an example of the links between the way patients are treated in the health service and NHS staffing policy.

As a matter of principle district health authorities should have a commitment to meet the needs of patients in their catchment area. The commitment required - which community health councils and community organisations should demand - is a commitment to meeting patients' needs in whatever way they find acceptable. In this case, this would involve taking steps to increase the number of female doctors employed in the district.

At the same time, the reasons why there are fewer women than men in the medical profession as a whole and particularly in the hospital specialties, need to be examined. At present the medical profession discriminates against women by penalising them in respect of promotion for taking time away to have children and making it very difficult to achieve work schedules which are compatible with bringing up children. It therefore is not enough for a health authority to state its willingness to employ more women; it has to take active steps to create the conditions in which women will find it possible to work and look after children.

The issue of racism in the health service is not going to disappear or be solved overnight. The understanding the Multi Ethnic Women's Health Project has is that it is possible to combat daily manifestations of racism as they affect patients (and staff) in the health service, but that the much more fundamental, structural changes needed to create equal opportunities will only be achieved by making the NHS accountable to the communities it serves.

THE PRINCIPLE OF ADVOCACY

Chaired by Shameem Habibullah and Judith Nesbit

In opening the conference Pam Hibbs, District Nursing Officer, defined an advocate as one who "pleads for another, a professional pleader" In the health service, the advocate's role is to plead for the patient, to guide the patient through the medical system and to promote the patient's interest in the way the patient considers appropriate. Advocacy usually takes place on two separate levels:

(i) that of the individual patient, where the advocate finds out information from the hospital for the patient, helps the patient understand the purpose and methods of investigations, treatments etc., and helps the patient make her own wishes known to the hospital;

(ii) that of the hospital, where the advocate's task is to bring to the attention of the relevant bodies anything in their policy or practices which is contrary to the patient's interests.

Although the Multi Ethnic Women's Health Project in Hackney is for non-english speaking women only, it is not an interpreting service. To the people involved in the Project the distinction between interpreting and advocacy is crucial. Both aim to improve communicaton between patients and staff but other than that the two types of service have very little in common. Interpreting services tend to be set up where hospital staff find it difficult to communicate efffectively with patients who do not speak english. The interpretor's role is to find out from the patient the answers to the staff's questions, and to relay to the patient the staff's wishes/directives.

Advocacy, however, is based on the idea that it is always difficult for patients to negotiate what happens to them in hospital on their own terms. The advocate's role (the exact reverse of the interpreter's role) is to find out from the staff the answers to the patient's questions and relay to the staff the patient's wishes.

This is how Shameem Habibullah, one of the project workers described the difference between being an interpreter and an advocate:

> When the Project first got under way, most people assumed that the main problem was one of language and what was needed was interpreters. We have never seen ourselves simply as interpreters. We have always wanted to be something much more active - health workers and advocates. Nothing changes if there is just interpreting, it is a one-way process. We would merely have transmitted the hospital's wishes and instructions to the patient. We want much more than that. We want to defend and stand with the woman, make the woman's wishes known also to the hospital so that it is a real two-way process, not just in understanding language but in changing what goes on in hospital if it is unacceptable to our women.

The key to the difference between interpreting and advocacy lies in her description of the workers 'wanting to be something much more active' and in the passage where she talks about the difference between the one-way process in which nothing changes as opposed to the two-way process in which it is possible to make changes in hospital practices which patients find unacceptable.

The argument for advocacy is based on the proposition that the relationship between patients and staff in medical settings is not equal and that the inequality in the relationship works to the patient's detriment. In Hackney, the Multi Ethnic Women's Health Project recognises that there is need for advocates amongst all types of patient, but believes that the need is particularly acute for female patients and patients who do not speak english. The reasons for this have already been outlined in the section on racism.

The NHS is an extremely large organisation and like other organisations of its size lacks flexibility. It does not respond easily or well to the different needs of individuals. It is also an hierarchical organisation in which various groups and professional bodies compete for power to control their own and each other's areas of work. The dominant group in the health service is the medical profession, which is predominantly both white and male.

In order to maintain their own position vis a vis one another and in relation to the patient, doctors and nurses jealously guard their own areas of expertise from the patient. Professional secrecy is one of the many aspects of patients' experience of hospital life which can cause anxiety. Rotas change, staff come and go, staff ask questions without explaining why they are asking them or how the patient's answers will be interpreted, treatments and investigations start and stop or change without the patient being told the reasons or their implications.

Much of the project workers' time is taken up with services which - in an ideal world - would be available to all patients. They try to make medical techniques intelligible to the women and to give them enough information about the alternatives to make their own choices about the type of delivery and care they require. But some aspects of their work are uniquely determined by the fact that they are working on behalf of black and ethnic minority patients in this particular hospital, in this particular area.

This last point is important. The principle on which the Project is based is that it reflects and represents the interests of the local black and ethnic minority patients. Within the Project itself, the health workers are committed to preventing and dismantling cultural stereotypes and assumptions which suggest that one can provide a service for individuals from black and ethnic minority groups which is uniform (e.g. "Turkish patients are like this ...", "Indian patients eat ..." "Muslim women ... etc.). The Project is not, and is not intended to be a blueprint which can be applied universally, throughout the country. In each area the composition of black and ethnic groups in the population differs and their needs in relation to local health services will be particular.

To understand the principle of advocacy and what makes the Multi Ethnic Women's Health Project in Hackney unique, one can refer back to Zohra Ali Zubair's account of her work, quoted in the preface. She said that the workers 'speak for the women of their own communities', and as part of that, accept that they may have to take up matters of interest to the patients with the health authorities. For example, they have questioned whether routine internal examinations need be carried out on pregnant women, especially when it means that a woman who would not wish to be seen by any man other than her husband has to be examined by a male doctor. They have taken up the issue of access to women doctors. They have raised the question of suitable food in hospital and have succeeded in getting Halal food provided. They have been involved in a review of the hospital's procedures for handling dead bodies which is a matter of particular concern to some patients.

The other element in the Project which gives it its distinctive character is the requirement that the workers should share the patients' experience in as many ways as possible. This is not something which would be required of an ordinary hospital interpreter. In the words of Hafize Ece, the Turkish worker on the Project:

> Our position is that we are speaking with the woman, we try to understand as a woman, as a mother - to see what she wants, what she needs and then we go back to the professionals and we say, "This is how she feels. She can accept that much", or "I can help her because I know her culture, and I know what she can and can't accept. I can find another way to talk to her".

RELATIONS BETWEEN LAY AND PROFESSIONAL HEALTH WORKERS

Chaired by Mariam Achhala and Luise Parsons

The Project employs five women chosen from the larger non-english speaking minorities in Hackney. No formal qualifications are required for the post, but in making the appointments the steering group looks for women who are strongly identified with and committed to their own communities and to the principle of advocacy. The women also need to have had personal experience of pregnancy and childbirth and to be articulate in english as well as in their first language.

Since the start of the Project there have been changes in the way the workers are trained, but the principles on which their training is based have not altered. The training is not like that of a professional health worker but is intended to support and to supplement what they know already (from their experience as women, as mothers and as members of their own community) in whatever way the workers themselves and the management of the Project feel is necessary. To be responsive to the workers' needs as they arise, training is as informal and flexible as possible. For example, their work in the hospital sometimes involves having to give women the news that there is something wrong with their child or that their child is dead. It seems obvious that where there is a health worker from the Project who knows the woman, she should be the one to give the bad news. However the health workers themselves find the task even more distressing than professional health workers because they have got to know the woman well before the baby is born and often have become her personal friend. These difficulties were discussed with the steering group and it was arranged that a number of the weekly training sessions set aside for reading and discussion should be led by a bereavement counsellor.

The formal elements in the health workers' training consist of a course in basic principles of midwifery, attendance at two booking clinics where they are taught how to take a history and book women in, a weekly three-hour session which may be used for reading, writing reports, preparation, discussion and regular meetings with the steering group.Although their training does contain these formal elements, great importance is attached to the continuous process of gathering information and learning from experience. The knowledge the health workers gather informally - about the workings of the hospital, the personalities and reputations and attitudes of the staff, individual patients and the potential range of their problems - is as important to their work as advocates as the knowledge they gain from the formal training sessions.

It should also be noted that since the start of the Project, members of the steering group and the staff of the hospital have themselves been engaged in a continuous process of learning, and that most of what they learn is taught to them by the workers. What they have learnt concerns patients, patients' perceptions of the service, gaps in the service, changes which are needed, obstacles to change and how to tackle them as well as the practical limitations to what can be achieved through advocacy.

The nature of the work

The account in the preface gives a fair indication of the range of activities and services in which the health workers are involved. At the conference attention was concentrated on the role of the workers in the Mothers' Hospital, but it should be noted that they also run groups and visit patients in the community and that some of their work (parenthood classes) is based in health clinics. The most obvious point to make is that their work does not respect the conventional lines drawn between medical and social problems which underlie the separation of health services from social services and voluntary services in the community.

Maraim Achhala, one of the project workers, told a story which illustrates the way that involvement with individual women takes the workers outside the hospital and into contact with a variety of institutions,organisations and services in the community. It also illustrates the perspective the workers bring to their work:

> We are working in the hospital, we don't take any professional job but we try to fill the gap when the need arises. To give an example: I saw a patient who was heavily pregnant walking with enormous trouble and difficulty in the booking clinic. I started to talk sympathetically to her and I found that the trouble had occurred when her first baby was born. I understood from her that she had had an epidural and had then been neglected. She wasn't followed up by any professional person. She complained about her pain at the hospital, to the midwife, to the health visitor, to her GP, but nobody cared for her. She was ignored and left to cope on her own at home with the help of her husband.
>
> It was really painful for me when I heard that she was suffering like this in her own home when there is all the care available. I explained her rights to her and I helped her complain about her GP who had neglected her for three years. With the help of the Community Health Council I also organised a meeting with the local GP and the Family Practitioner Committee in her own home. Well, I was surprised. The GP had prescribed her morning-sickness pills without a pregnancy test and had not referred her until she was seven months pregnant to the hospital. Now there is a question, because of the three year long gap, it wasn't clear whether we should hold a formal or an informal hearing of the FPC. The Family Practitioner Committee was proposing an informal hearing and saying it would be better if we went ourselves and discussed with the GP how much he had neglected this patient. But my aim is to have a formal hearing - even if the patient loses - because I want to improve the health service. I'm not just worried about one patient, but about how many other women are suffering like this from careless GPs or careless professional people."

The health workers do not actually do the work of a professional health worker, but they may do some parts of it. Their first contact with the women is in the booking clinic where they take the woman's history (a task the midwife usually performs) and book her in. The health workers do not wear uniforms and they introduce themselves by their first name. This is to encourage the women to feel relaxed and to see them as a potential friend, someone who is on their side. The workers believe that a uniform would suggest that they considered themselves different, and perhaps even superior to them, and would certainly suggest that they were part of the hospital staff. They say that uniforms create a psychological barrier which would stop the women talking freely to them.

Conflicts and resolutions

The arrival of the health workers and their presence in the hospital has produced tensions and difficulties for them and for the hospital staff. Where there are particular conflicts - as in one case where a staff midwife refused to let the health worker see a patient's notes - an attempt is always made to resolve it immediately. If this fails, the health worker can call on the nursing officer with whom she liaises who will discuss the problem with the officer responsible for the member of staff. This is one of the changes which has been made as the Project has gone along. At the outset the workers did not have this kind of institutional back-up inside the hospital and conflicts were much less easily resolved.

Some of the difficulties between the health workers and the staff are amorphous and hard to pin down. There may be no single episode to point to, but the atmosphere can be tense and either the workers or the staff, or both, can feel generally frustrated and blocked. For the workers, the major difficulty has been the attitude of some members of staff, nurses and paramedical workers especially, towards them and their work. When they first started in the hospital they were often asked disparaging questions about their 'qualifications' as health workers. They were put in the position of having to over-hear racist comments about themselves and the patients. Initially too they suffered the hostility of nurses and midwives who felt threatened by them. It was felt that if 'untrained' health workers from the Project were allowed to take over parts of the midwives' jobs, then this would devalue the work of the midwives. As time has passed, and the health workers and hospital staff have grown used to one another and the nature of their work has become clearer, the midwives' anxieties have been quelled. Janet Bradshaw, Deputy Director of Nursing Services and Professional Head of Midwifery addressed these issues at the conference. She pointed out that the effect of the Multi Ethnic Women's Health Project has in fact been to extend the role of the midwives. There is such a demand for their services that in future they will be running clinics in the community.

For the staff, there has been discomfort and distress at having their attitudes and work practices questioned by the Project workers as well as the initial fear among some that their jobs were under threat. The tension is less now partly because it has become clear that their areas of work do not overlap, but also because senior nurses spend time explaining the Project and how it works to new members to staff. A minority of staff, notably amongst clerical and paramedical workers, continue to resent the workers.

Autonomy

The health workers from the Project are accountable to the steering group. They each spend a day in the CHC office where they do paperwork, make phone calls, hold meetings and organise their work rotas. There is always someone "on duty" and they take turns to cover weekends and emergencies. The political arguments for self-management of their work by the workers and for the independence of the Project from NHS management are examined below. From a practical point of view, the present arrangements suit the workers well: they are able to make contact with the women in the clinics and have the freedom to decide whether they should stay with a particular woman or leave her to attend to someone else, depending on their own judgement of each woman's needs.

The arrangement suits the hospital staff less well and nursing officers in particular would like to have more control over the workers when they are in the hospital. They complain that they cannot get hold of the workers when they want them and that the situation would be improved if they were in charge of their work schedules and their disposition within the hospital. In large part the complaints have arisen because the staff find the project workers' services so useful. Without them the staff continue to have great difficulty communicating with non-english speaking women. They particularly value the workers' role in taking patients' histories and teaching parentcraft classes.

The Project as a whole has resisted all attempts to take control of the workers' time in hospital but has come to an arrangement whereby liaison between the health workers and hospital staff is conducted always through the same nursing officer. This has helped the problems of communication and coordination between all parties.

During the discussion at the conference workshop concern was expressed over whether the health workers can maintain their autonomy as patient advocates if they spend long periods of time working in hospital. It was suggested that their role, negotiating between the separate cultures of the women and the hospital, is inherently so stressful that no one should remain in the job for any length of time. Some people felt that it might be difficult for the workers to resist being drawn into identifying with the hospital staff and adopting their view of patients. It was noted, for instance, that there had been talk of 'defaulters' and 'late attenders' during the workshop, and that these are terms/labels which professional health workers might, but advocates ought not, to apply to patients.

There was also a question about whether, after doing the job for some time, the health workers might not feel tempted to take a professional qualification.

To all these anxieties and questions, Mariam Achhala replied firmly that her experience in the hospital had not separated her from her community. On the contrary, her background, her culture and her religion have continued to be of central importance in her life, and she has not found either the role of the professional health worker or the view that professional health workers have of patients especially appealing or seductive.

MANAGEMENT OF THE PROJECT

Chaired by Zohra Ali Zubair and Fedelma Winkler

Questions of finance and managerial control in the formal relations between the Multi Ethnic Women's Health Project and the NHS should be considered separately. The Project has been fortunate in having had an independent source of finance in the monies made available by Inner City Partnership. In other parts of the country this type of financial assistance for an advocacy scheme would be less readily available. The feeling at the conference was that as a matter of principle the DHSS should make funds available to employ advocates for black and ethnic minority patients, and community health councils and community organisations should bring pressure to bear on the Department to ensure it makes this commitment to equal opportunities.

Regardless of finance however, it is essential for managerial control to rest outside the health service and with community organisations. Close contact and cooperation with health service staff is important: the workers would not be able to do their job if they did not have easy access to patients in the hospital. Just as important, their position has to be such that their comments, criticisms and suggestions will be taken seriously. The relationship with the health service therefore has to be close enough for them to be able to do their work effectively, without being so close that they become absorbed into the service. Were they to be made responsible to health service managers their role as independent spokesperson for the patient would be undermined.

It is not in the direct interest of managers and administrators to promote criticism of the services for which they are responsible. For reasons which are not difficult to understand, NHS managers faced with the prospect of having to provide for black and ethnic minority patients, have preferred to appoint interpreters rather than patient representatives/advocates. The feeling of the Multi Ethnic Women's Health Project, which was reflected in the conference as a whole, is that an advocacy scheme run from within the health service is almost a contradiction in terms and would - very rapidly - become an interpreting service.

In Hackney, the necessary balance in the relationship with the health service is achieved in a formal sense through the structure of the steering group. This is made up of representatives from local community organisations, NHS staff and the Community Health Council. The Project owes much of its success to the sympathy and support it receives from the senior NHS staff involved in the steering group, and especially from senior nurses.

It is absolutely essential for local community organisations to be involved in the management of an advocacy scheme. This is the only way in which the aims - to improve the position of black and ethnic minority patients and workers in the NHS - can be realised. The health authorities cannot afford to discount patient advocates who have the public support of representatives from local community organisations. Equally the representatives' experience of being in close contact with health service staff is invaluable to their communities.

Two questions were raised at the conference by people interested in promoting advocacy in their own areas. 'Is it possible to transform an existing interpreting service into an advocacy service?' and 'What are the initial steps which need to be taken in setting up a project?'

The answer to both questions was the same. Community participation in and control over the project is fundamental, and may take a long time to achieve. Remembering that health service staff must also be involved, the negotiations to achieve a management structure which is acceptable to both sides and effective, can be very lengthy. In Hackney, for example, there are a number of organisations which represent each of the different black and ethnic minorities, and it is important that the project is seen to be representative of all relevant groups. The advice from members of the Multi Ethnic Women's Health Project was not to be discouraged by this, and above all, not to try and cut political corners to save time. The Project's strength in relation to the hospital and health authorities comes from the community, and without the backing and support of local organisations it could not be effective.

Photo: Mike Abraham / Networks

A MEDICAL PERSPECTIVE

Neville Wathen, Consultant Obstetrician and Gynaecologist

This unique and ambitious health project, has indisputedly improved the quality of service to the non-english speaking women at the Mothers' Hospital. These women now have a friend at court, a health worker with whom they can identify and who in turn provides information about the National Health Service, provides advice, health education and emotional support. The emphasis placed on health education is very important. As a result, the women feel more confident and more satisfied with the service which they are receiving. This situation should in principal improve attendance figures at clinics. Butler and Bonham in their British perinatal mortality survey*1 showed that perinatal loss is increased by 500% in women who have total lack of antenatal care. Women who default frequently are also at higher risk.

Improved attendance

I have compared two randomly selected groups of non-english speaking women. The first group attended the antenatal clinics in 1979 before the Multi Ethnic Health Project got under way, and the second group is from 1984 with the project now fully established. In the 1979 group there were 64 visit defaults per 100 women compared with 44 per 100 women in the 1984 group. As this trend was not found in a similar randomly selected group of english speaking women, who in fact showed an increase in incidents of default, I believe we can justifiably attribute at least some of this improvement to the Project.

Counselling

The health workers provide direct assistance to the medical and midwifery staff in a number of ways. More information is available about the patient and there is a better understanding of the patient and her individual needs, both vitally important points. A major contribution is being made in the area of counselling. Through education and in-house experience, the workers are now familiar with various genetic disorders and congenital anomalies, for example, Down's Syndrome, thalassaemia, and neural tube defects. They also have a knowledge of the pre-natal diagnostic techniques available to diagnose these conditions in pregnancy and of the risks involved in these techniques. They are able to discuss all these aspects with the women in terms which they understand, a task which is time-consuming and virtually impossible without a complete command of the woman's own language.

Counselling and emotional support are also provided where the woman loses her baby or delivers an abnormal baby. This may be very painful to the health workers as they have pointed out.

Nutrition

The health workers have placed considerable emphasis on health education and hygiene. It is difficult to evaluate this in concrete terms, but, I have looked once again at the two groups of both english and non-english speaking women in an attempt to determine any change which could be attributed to an improved nutritional status in the non-english speaking women. My first consideration was haemoglobin concentration. Iron deficiency anaemia is a common disorder in pregnancy which is associated with a large number of obstetric complications. All pregnant women are encouraged to take iron supplements. These are provided by the NHS so this eliminates to some extent variations due to different economic situations with different patients. In the 1979 group of non-english speaking women a significant fall in haemoglobin was seen in about 20% of women, compared with 16% in the 1984 group. This is not a significant change. However, there was a difference in the number of women who showed a significant increase in their haemoglobin levels. In the 1979 group 26% of the women showed a significant increase compared with 40% in the 1984 group. That is an increase of 26 to 40%. No trend was observed in the english-speaking control group.

Birth weight

My second consideration was that of infant birth weight where once again a change was observed between english and non-english speaking groups. In the 1979 group of non-english speaking women, 22% of the women delivered babies weighing 2.5 kilograms or less. That is quite a remarkable number. In the 1984 group the figure was 10%. This is a significant fall which I would like to confirm on a large sample. This trend was not present in the english speaking group of women. The figures for both haemoglobin levels and birth weights show a change for the better.

Expansion into community services

Looking to the future, I think that even more significant improvement may be obtained by expanding the Project into community services. In support of this claim, I can tell you that 46% of the non-english speaking group of women attending the ante-natal clinics were already 20 weeks pregnant or more when they booked for their ante-natal care, and there has been no improvement in this figure from 1979 to 1984. These women may, therefore, be too late to benefit from pre-natal diagnosis and too late to benefit fully from the health education provided by the health workers.

Education to encourage early booking is required. Moreover, 40% of all the pregnancies were described as 'unplanned', suggesting that the family planning services are not effectively reaching this group of women. Perhaps the clearest indication that expansion into the community is required comes from the fact that 11%*2 of all Hackney babies require hospitalisation within the first year of their life. In some areas of Hackney the admission rate is as high as 18%*2. The babies of non-english speaking women have been identified as contributing significantly to this number of admissions.

The Multi Ethnic Health Project within the Mothers' Hospital has been an undoubted success. Expansion of the project into community services, into areas of primary health care and into paediatric hospitals must be a priority.

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THE DISTRICT PERSPECTIVE

Sian Griffiths, Community Physician

The success of the CHC initiative has been widely recognised. At the Faculty of Community Medicine training conference, community physicians were pointed in the direction of Hackney if they wanted to see a model of care for ethnic minorities. Recent publications also recommend the approach.*1,2

As an objective observer I would like to congratulate all those involved in this project: the workers; the CHC; the health service staff. All groups have been essential to the Project, and it is the liaison between non-professionals and professionals, coordinated by the CHC, which has been the key to developing effective provision of care.

From the District perspective several lessons have been learnt:

1. it is possible to have community participation within the health service setting - the workers are based in the antenatal clinic.
2. non-professionals and professionals can work together.
3. awareness of the importance of advocacy and not merely translation.
4. increased staff awareness in establishing the cultural perspective of patients' needs.
5. the CHC has a positive role to play and can be effective in changing health practice within the District.

This Project started with the aim of providing support in the antenatal period to women whose first language is not english. Already, as the workers have described, they are becoming involved in wider health issues. The scheme will be extended to other care groups beyond the antenatal period, not only in hospital but also in the community services.

One idea is to extend advocacy to the child health and family planning services where understanding of cultural values is essential to an effective service. Another area where advocacy could be important is in prevention. However, there is a danger in being too 'problem' orientated. A recent paper in the BMJ showed that Indian and Pakistani mothers in Bradford were more likely to have had their children immunised.*3

Hackney's need for health advocacy schemes

In his introduction to 'Inside the Inner City', Paul Harrison describes the inner city as: "a microcosm of deprivation in which are concentrated the worst housing, the highest unemployment, the greatest density of poor people."*4 He was, of course, describing Hackney. In 1983, the adult male unemployment rate in Hackney was 27.3% which is 80% above the national average. 70% of housing is owned by the public sector. The remaining 30% is divided between gentrified properties and run down, poorly built Victorian properties. Small area statistics from the 1981 census show that Hackney appears in the worst 10 authorities for five out of the eight indicators of deprivation used.*5.

To quote the Acheson Report: "The combined effects of social deprivation, poor environment, high mobility and the relatively high proportion of semi-skilled and unskilled manual groups, together with the worse than average experience of certain types of disease, provides a special challenge for the provision of services which are already severely extended."*6

As Britain's poorest borough, Hackney also had the third highest percentage of households (28%) whose head was born in the New Commonwealth or Pakistan.*4 This is not to suggest that ethnic group is of itself an indicator of deprivation. It is an additional factor to be considered, alongside the other complex social factors of a district such as Hackney.

The arguments about whether or not to include questions about ethnic group in the the census are complex. However, accurate information on the social and economic position of minorities is necessary as a base against which to measure existing service delivery, as a means of identifying special (and possibly localised) needs and as a tool for planning and dissemination of more appropriate services.

Unfortunately, no such accurate information is available and so, to assess Hackney's needs, we resort either to special surveys or indirect measures.

In 1978, the General Household Survey asked the question "which of these ethnic groups do you belong to?". The results showed that:

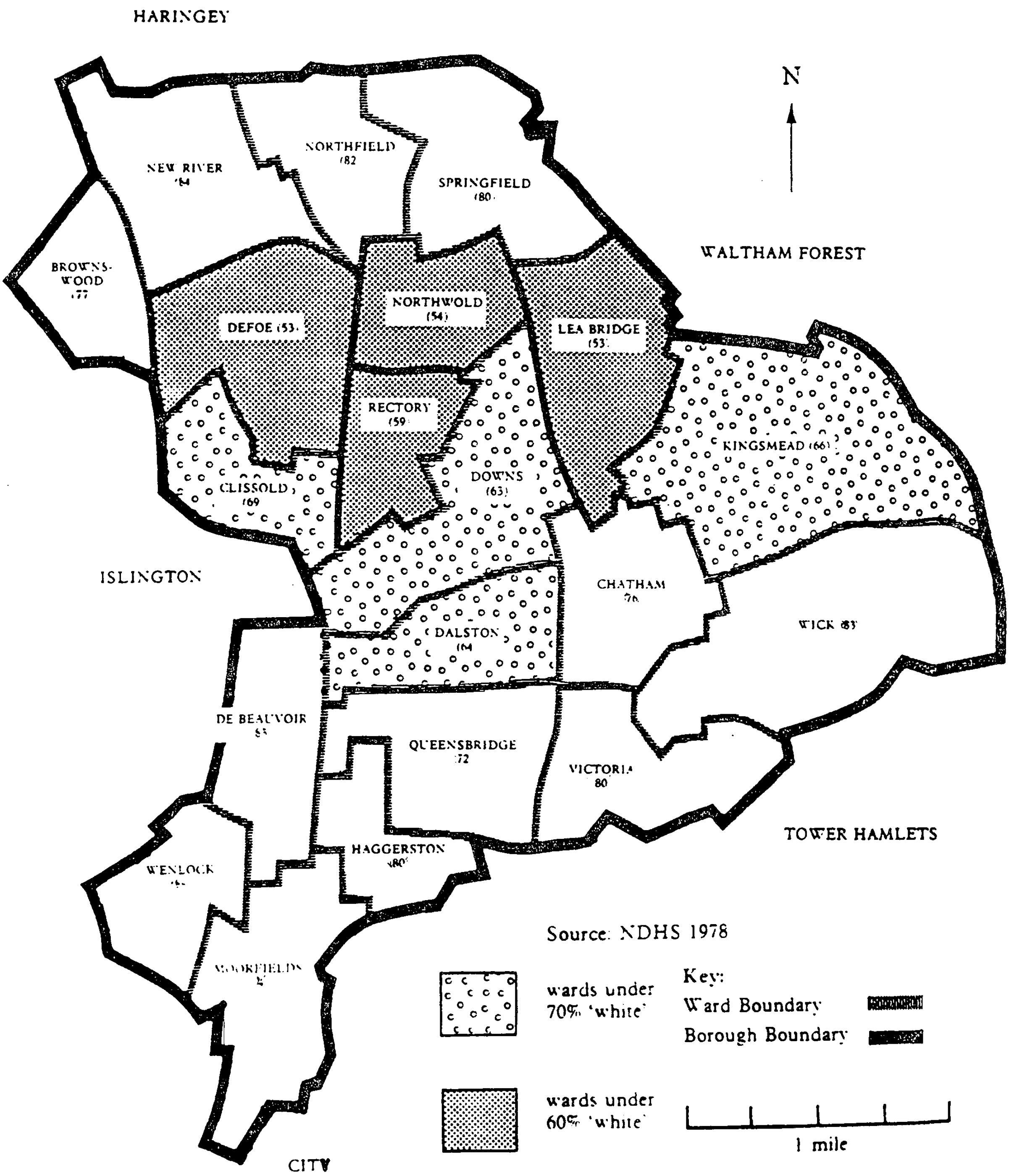
1. ethnic minorities were concentrated in certain parts of the borough (see fig. 1).

2. those from the Indian sub continent were more mobile than the others, and more likely to have come into the borough in the last year (fig. 2).

3. there were differences in the age distribution between the ethnic groups (fig. 3), with a higher percentage of under 20s amongst those from the Indian sub continent.

OPCS figures for numbers of live births to mothers by birth-place of mother (figs. 4 and 5) showed Hackney to have a higher percentage of mothers born outside the UK and mothers born in the New Commonwealth and Pakistan. What do these statistics imply? It would seem, even considering the limitations of the figures, there will be a need for health advocacy for ethnic minorities for a good many years yet.

FIG 1 WARDS OF THE LONDON BOROUGH OF HACKNEY



Source: NDHS 1978

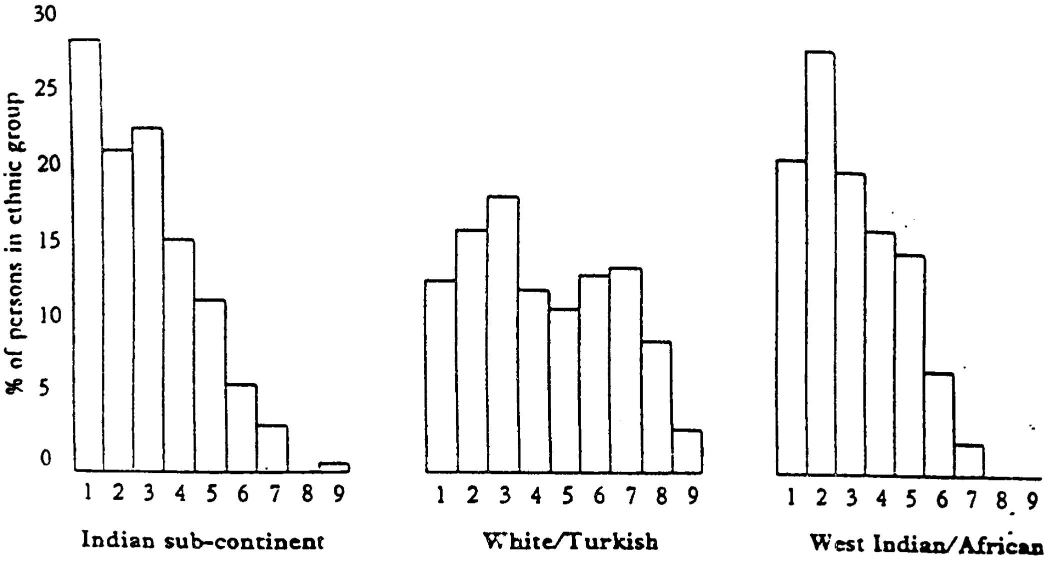
Source: Hackney Borough Profile *7

FIG 2 Addresses One Year Prior to 1978 NDHS

Percentages of all residents in group	White/Turk	WI/Afr	Indian sub-continent	TOTAL
SAME	87.1	84.8	81.9	86.0
OTHER	13.9	15.2	18.1	14.0
TOTAL	100	100	100	100
Percentages of those residents in group with different address				
HACKNEY	52.9	60.7	42.3	54.5
OTHER LONDON	30.6	31.0	42.4	31.2
REST OF ENGLAND	9.7	3.7	8.4	8.2
OUTSIDE ENGLAND	6.8	4.6	6.8	6.1
TOTAL	100	100	100	100

Source: Hackney Borough Profile *7

FIG 3 Ethnic groups by age for Hackney 1978



Age groups:
1. 0-9
2. 10-19
3. 20-29
4. 30-39
5. 40-49
6. 50.59
7. 60-69
8. 70-79
9. 80+

Source: Hackney Borough Profile *7

FIG 4

Birthplace of mother	PERCENTAGE OF MOTHERS (%) 1971	1975	1979	1981
United Kingdom	88.1	87.9	86.9	86.9
Total alongside United Kingdom	11.3	11.9	13.1	13.1
New Commonwealth and Pakistan	5.8	6.6	8.2	8.4

Source: OPCS FMI 83/2 Monitor

FIG 5 LIVE BIRTHS BY BIRTHPLACE OF MOTHER 1981

Rates for: Place of birth	% live births born outside UK	Newborn in Commonwealth and Patkistant
England and Wales	13	8
GLC	34	22
Hackney	47	34

Source: OPCS FMI 83/3 Monitor

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APPENDIX I

KING EDWARD'S HOSPITAL FUND FOR LONDON
King's Fund Centre

AN EXPERIMENT IN ADVOCACY:
The Hackney Multi Ethnic Women's Health Project

Monday, 4th June 1984

PROGRAMME

ALL THE CONTRIBUTORS WORK IN CITY/HACKNEY DISTRICT

Morning Session Chair: **Pam Hibbs**, District Nursing Officer

10.00 am Coffee and registration

10.30 Introduction from the Chair

10.35 From ideas to practice: interpreting to advocacy
Fedelma Winkler, Secretary, Community Health Council

11.05 The workers' perspective

Mariam Achhala	Project Worker
Zohra Ali Zubair	Project Worker
Hafize Ece	Project Worker
Shameem Habibullah	Project Worker
Monowara Talukder	Project Worker

11.30 Questions

11.40 The professional perspective
Janet Bradshaw, Deputy Director of Nursing Services.
Professional Head of Midwifery

Neville Wathen, Consultant Obstetrician & Gynaecologist

12.00 The district perspective
Sian Griffiths, Community Physician

12.15 Questions

12.30 LUNCH

Afternoon Session Chair: **Marie Lewis**, Community Relations Worker
Chair of the Hackney Project

1.45 Discussion Groups

3.15 TEA

3.30 Outstanding issues and questions to the panel

4.30 Summary from the Chair.

AN EXPERIMENT IN ADVOCACY:

The Hackney Multi Ethnic Women's Health Project

DISCUSSION GROUPS 1.45 - 3.15 pm

Participants are asked to choose the group they would like to take part in and to "sign up" when they register on 4 June.

GROUP 1 Professionals and lay workers

Leaders: **Mariam Achhala,** Project Worker
Luise Parsons, Community Physician

The Hackney project employs women with experiential knowledge to speak for other women. This group will explore participants' feelings about this aspect of the project, including the advantages for professionals and for users and why health workers sometimes see it as threatening.

GROUP 2 Why not an interpreting scheme?

Leaders: **Shameem Habibullah,** Project Worker
Judith Nesbit, teacher of English as a second language

This group will discuss who benefits and who loses by the setting up of a health advocacy scheme rather than an interpreting scheme for non English speaking women.

GROUP 3 Racism in the NHS

Leaders: **Hafize Ece,** Project Worker
Colin Franklin, General Practitioner and President, Hackney CRE

A project such as the Multi Ethnic Project can make racism overt. How do we perceive and tackle racism in the NHS and how ought it to be tackled.

GROUP 4 Practicalities of starting and running the scheme

Leaders: **Zohra Ali Zubair,** Project Worker
Fedelma Winkler, CHC Secretary

Fedelma Winkler and Zohra Ali Zubair will answer questions on details of the project and offer their experience and help in working out strategies for those who are trying to get a similar scheme off the ground.

APPENDIX II

King Edward's Hospital Fund for London

King's Fund Centre
126 Albert Street London NW1 7NF

AN EXPERIMENT IN ADVOCACY:
The Hackney Multi Ethnic Women's Health Project

Monday, 4th June 1984

PARTICIPANTS

Ms Z ABBASI	Health Liaison Officer	Oxfordshire CCR
* Mrs M ACHHALA	Project Worker	Hackney Multi Ethnic Women's Health Project
Ms R ADAMS	Community Relations Officer	Harrow CRC
Mrs G AHMED	Social Worker	Leicester Royal Infirmary Maternity Hospital
Ms P AKHTAR	Groupworker Representative	Newcastle Family Service Unit Newcastle Inner City Forum
Dr A AMOS	Senior Scientific Officer Department of Community Medicine	Royal Free Hospital
Mrs F APARGEE	Steering Group	Hackney Multi Ethnic Women's Health Project
Mr H S BAINS	Member	South Derbyshire CHC
* Ms J BRADSHAW	Professional Head of Midwifery Deputy Director of Nursing Services	The Mothers Hospital City & Hackney HA
Mrs C BROWN	Member	East Birmingham CHC
Ms P BROWN	Senior Nurse (Specialist)	Tower Hamlets HA
Ms E CAIRNCROSS	Joint Secretary	Greenwich CHC
Mrs A N CHOWDHURY	Community Health Worker	Maternity Support Liaison Scheme
Mrs R CHOWDHURY	Women's Worker	Dame Colet House, E.1
Ms B CLARK	Steering Group	Hackney Multi Ethnic Women's Health Project
Ms M COLYER	Acting Director of Nursing Services (Community)	Tower Hamlets HA
Ms J CORNWELL	Rapporteur	King's Fund Centre
Ms P DANIEL	Lecturer in Parent Education	Hackney Adult Education Institute
Ms E DAVIES	Chair	City & Hackney CHC
Mrs D DORRELL	Member	South Derbyshire CHC
Mrs E F DOUGLAS	Co-opted Member Ethnic Minority Group	Cardiff CHC
Mrs A F DOYLE	District Health Education Officer	Blackburn, Hyndburn & Ribble Valley HA
* Mrs H ECE	Project Worker	Hackney Multi Ethnic Women's Health Project
Ms R EVANS	Co-ordinator	The Maternity Alliance
Mrs E M FARUQI	Assistant Director of Nursing Services (Community)	Haringey HA
Miss B FERGUSON	Nursing Officer (Continuing Care)	Queen Elizabeth Hospital for Children, E.2
Mrs W FERNANDO	Midwifery Sister	Leicester General Hospital
Mrs N FILTNESS	Member	Lewisham & N. Southwark HA
Ms J FINUCANE	Assistant	South Manchester CHC
Ms R FORD	Community Worker, Easton	East Bristol Institute of Adult Education
Dr C FRANKLIN	GP President	Hackney Hackney CRE

Miss P N GANGANI	Social Worker	Warwickshire Social Services
Mr G GIRVAN	Secretary	Bexley CHC
Ms P GORDON	Project Officer	King's Fund Centre
Ms H GRAHAME	Vice-Chairman	Bloomsbury CHC
* Dr S GRIFFITHS	Senior Registrar in Community Medicine	City & Hackney HA
* Mrs S HABIBULLAH	Project Worker	Hackney Multi Ethnic Women's Health Project
Mr I HAIG	Senior Community Relations Officer	Hackney CRE
Mrs J A HAMMOND	T.E.S.L. Tutor (Health)	Queensway Centre, Bletchley
* Ms P HIBBS (Chair)	District Nursing Officer	City & Hackney HA
Mrs P HILL	Health Visitor	Newham HA
Ms M HINSHELWOOD	Health Services Officer	Commission for Racial Equality
Ms J HUGHES	Project Officer - London	King's Fund Centre
Mrs H JETHWA	Social Worker	Leicester Social Services
Mrs C KALLIE	Community Liaison Officer	Oxfordshire CCR
	Representative	Oxfordshire CHC
Mrs V KAVRA	Community Worker	Barking & Dagenham CRE
Ms A KHAN	Steering Group	Hackney Multi Ethnic Women's Health Project
	Member	Hackney Muslim Women's Council
Ms T KHAN	Information Officer	Centre for Ethnic Minorities Health Studies, Bradford
Ms A KINGSBURY	Member	Camberwell CHC
Mrs E KYNCH	Vice-Chairman	South Manchester CHC
Ms U LADWA	Co-opted Member Ethnic Minority Group	Cardiff CHC
Mr M LAKHANPALL	Research Assistant Department of Community Medicine	Islington HA
Ms G LAMBERT	Co-ordinator Black and Ethnic Minority Link Worker Project	Haringey CHC
Ms C LANGRIDGE	Secretary	Wandsworth CHC
* Ms M LEWIS	Community Relations Worker	Hackney
(Chair)	Chair of Steering Group	Hackney Multi Ethnic Women's Health Project
Ms A McGREGOR	Health Education Officer	Bradford & Airedale Health Education Unit
Mr N MALIK	Nursing Officer (Health Visiting)	Newham HA
Ms V MARTINS	Social Welfare Officer	Manchester CCR
Ms L MASSIE	Editor INTERCOM	MIND
Mr N MAYS	Senior Research Officer Department of Community Medicine	Islington HA
Mr R J MAXWELL	Secretary	King Edward's Hospital Fund for London
Ms H MILLAR	Organiser English for Pregnancy Scheme	Bristol
Ms D MORLEY	Member	City & Hackney HA
Ms D MUKUMA	Senior Community Relations Officer	Croydon CCR
Ms T MUNBY	Post Graduate Social Work Student	Oxford
Ms J NESBIT	Steering Group	Hackney Multi Ethnic Women's Health Project
Mrs S J O'CONNOR	Assistant Director of Nursing Services (Midwifery)	Wandsworth HA
Mrs C OLOKOCANA	Midwifery Sister	The London Hospital
Ms T ONG	Midwifery Sister	The London Hospital
Ms S PANCHAL	Clerical Officer	Bristol Social Services
Dr L PARSONS	Registrar in Community Medicine	City & Hackney HA
Miss C PITTAWAY	Health Visitor	Tower Hamlets HA

Ms U PRASHAR	Director	Runnymede Trust
Ms A REMTULLA	Health Visitor	Islington HA
Mrs J RHODES	Member	Hillingdon CHC and CRC
Lady RICHES	Vice-Chairman	City & Hackney HA
Ms J SCOTT	Assistant Community Relations Officer	Peterborough CCR
Ms G SHARPE	Sub-Committee Chairperson	Rochdale CHC
Mrs S SIBSON-TURNBULL	Convenor Working Group on Women's Health	Cambridge CHC
Ms M SKELCHER	Member	Central Birmingham CHC
Mrs C SKINNER	Senior Health Education Officer	Redbridge HA
Miss S M SPENCER	Senior Nurse Manager - Midwifery	Westminster Hospital
Ms M STENHOUSE	Health Visitor	Greenwich HA
* Mrs M TALUKDER	Project Worker	Hackney Multi Ethnic Women's Health Project
Ms C THOMAS	Research Officer	West Birmingham CHC
Mrs J THOMAS	Secretary	Bradford CHC
Dr P THOMPSON	Senior Medical Officer (Child Health)	Waltham Forest HA
Mr A TREASURE	Community Unit Administrator	Newham HA
Mr D TREDEA	District Health Education Officer	Dartford & Gravesham HA
Ms M TRIVEDI	Social Worker	Leicester General Hospital
Mrs A TRUESDALE	Outreach Working Party	National Childbirth Trust
Mrs V TUCKER	Community Worker	Barking & Dagenham CRE
Ms P UDDIN	Co-ordinator	Maternity Support Liaison Scheme
Mrs J VAGHELA	Midwifery Sister - Antenatal Clinic	Leicester General Hospital
Miss R VERMA	Member	Wycombe CHC
	Social Worker	Wycombe CRC
Prof H WALLER	on sabbatical in London from	Luneburg Polytechnic
Ms M WANN		London Community Health Resource
* Mr N WATHEN	Consultant Obstetrician and Gynaecologist	The Mothers Hospital
Mrs M WATLING	Member	Rotherham CHC
Ms C WATSON	Journalist	Nursing Times
Ms A WATT	Development Officer	Community Health Initiatives Resource Unit
Ms S WESTCOMBE	Steering Group	Hackney Multi Ethnic Women's Health Project
Mrs L WHITESIDE	Community Relations Officer (Education)	Croydon CCR
Mr T WHITFIELD	Member	Bradford CHC
Miss M F WILLIAMS	Director of Midwifery Services	Dartford & Gravesham HA
* Ms F WINKLER	Secretary	City & Hackney CHC
Ms S WOODS	Steering Group	Hackney Multi Ethnic Women's Health Project
Mr A WRIGHT	District Health Education Officer	S.W. Hertfordshire HA
Ms E YAYALI	Steering Group	Hackney Multi Ethnic Women's Health Project
Ms J YUNG	Community Unit Administrator	Tower Hamlets HA
* Mrs Z A ZUBAIR	Project Worker	Hackney Multi Ethnic Women's Health Project

* denotes speaker