A USER PERSPECTIVE



Views on London's acute health services

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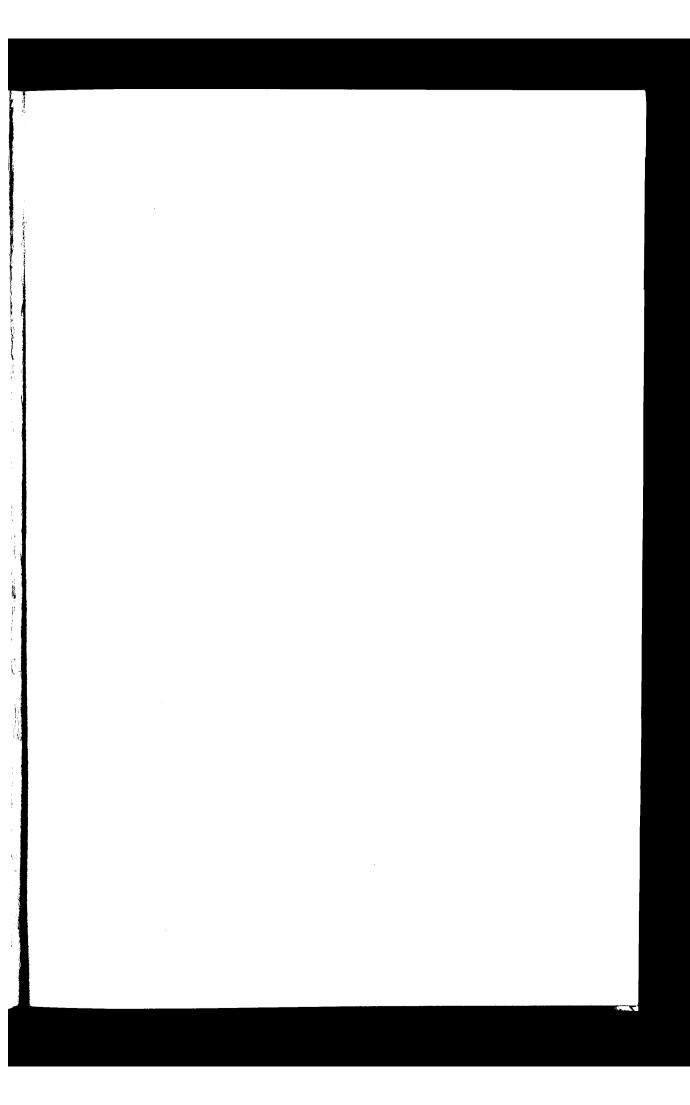
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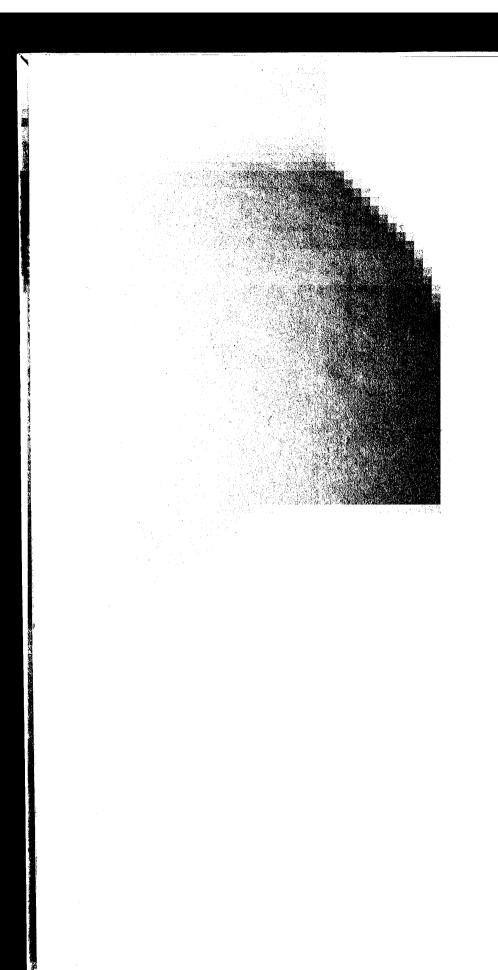
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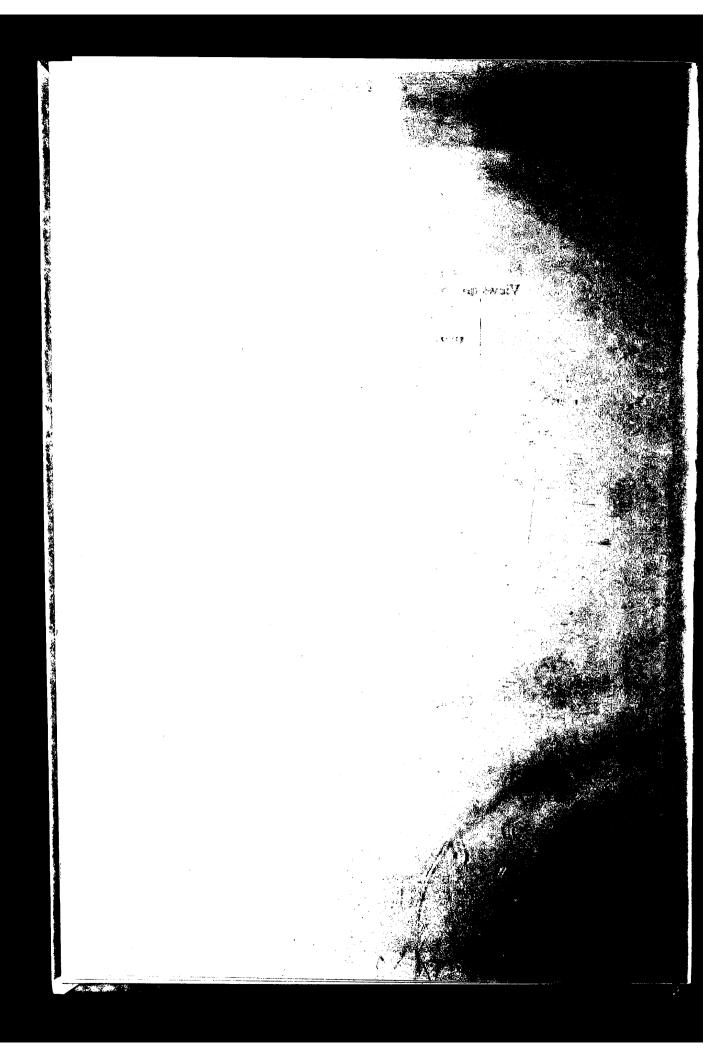


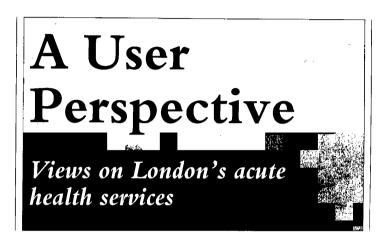


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A User Perspective Views on London's acute health services





Paul Martin, Richard Wiles, Belinda Pratten, Sarah Gorton and Jessy Green

Edited by Nikki Joule and Ros Levenson

Greater London Association of Community Health Councils





for the King's Fund Commission on the Future of Acute Services in London

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Contents

Appendix 1: The symposia 178

References 191

Appendix 2: Participating organisations 188

	List of figures and tables 6
	The authors 7
	Acknowledgements 8
	Foreword 9
	Executive summary 12
	List of abbreviations 15
	Part 1 Users and acute services in London
1	Introduction: The future of health services in London 19
2	The study – gaining a user perspective 22
3	Using London's acute services 27
4	Are acute services relevant to the needs of Londoners? 55
	Part 2 Acute care for older people
5	Introduction: Elderly people and health 69
6	Audit of services 72
7	Looking to the future 100
	Annex 104
	Part 3 Acute care for single homeless people
8	Introduction: Homeless people and health 113
9	The health care needs of homeless people 115
0	The homeless care package 123
1	Acute mental health services and single homeless people 150
2	Discussion 162
	Part 4 Conclusion
3	Improving the quality of acute services in London 169

FIGURES AND TABLES

- Figure 6.1 Hospital admissions per 1,000 district residents aged over 65 73
 - 6.2 Emergency admissions per 1,000 district residents aged over 65 73
 - 6.3 Elective admissions per 1,000 district residents aged over 65 73
 - 6.4 Hip replacements per 1,000 district residents aged over 75 74
 - 6.5 Knee replacements per 1,000 district residents aged over 65 74
 - 6.6 Cataract surgery operations per 1,000 district residents 74
 - 6.7 Pressures against improving the health service 75
 - 6.8 District nurses per 100,000 district residents 79
 - 6.9 Percentage of patients from inner London districts aged over 75 discharged from general wards, who had occupied a bed for over 28 days 79
 - 6.10 Percentage of patients from outer London districts aged over 75 discharged from general wards, who had occupied a bed for over 28 days 79
 - 6.11 Geriatric beds in inner London districts as a percentage of beds on general wards 82
 - 6.12 Geriatric beds in outer London districts as a percentage of beds on general wards 82
 - 6.13 Percentage of patients from inner London districts in acute specialties aged over 75 82
 - 6.14 Percentage of patients from outer London districts in acute specialties aged over 75 83
- Table 6.1 Waiting lists in London districts for the four surgical specialties 75
 - 10.1 Accommodation status of homeless people who have registered with a GP in Camden, Islington and City and East London FPCs 124
 - 10.2 Location of registration with a GP of homeless people in Camden and Islington 124

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FOREWORD

The Beveridge Report, containing the blueprint for the National Health Service (NHS), was published in 1942. It was a bestseller, with immense queues of people waiting to buy it. Some 600,000 were sold, and its proposals were greeted with enthusiasm as a beacon to aim for in the wartime gloom.

In 1990 the National Health Service and Community Care Act was passed, and in spite of the multi-volume White Paper which preceded it and the intense debate among politicians and professionals in the NHS, the public response has been perplexity and confusion rather than enthusiasm.

The relative lack of public understanding about, and enthusiasm for, the changes which came into being in April 1991 does not denote a lack of interest in the NHS. Rather, it signifies a fear that this institution, much loved in spite of its shortcomings, is at risk of destabilisation. Although knowledge and understanding of the legislative changes are increasing, it remains the case that the public (and no doubt many NHS managers too) are waiting to see how the situation works out before greeting it with any enthusiasm whatsoever. Moreover, it is plain that whatever the impact of the changes, Londoners will be affected in particular and profound ways over the next few years.

The King's Fund Commission on London's acute health services is, therefore, sitting at a crucial time. The Commission's deliberations may well affect the situation into the next century. We therefore warmly welcome the Commissioners' commitment to taking seriously a user perspective in considering the past, present and future of acute health care in the capital.

The Greater London Association of Community Health Councils (GLACHC) is uniquely placed to provide a user perspective. GLACHC has twenty-seven London Community Health Councils (CHCs) in membership, covering virtually the whole of Greater London. We provide a conduit for communication to, from and between London CHCs and are therefore in an excellent position to gain an informed overview of the issues that concern users.

GLACHC is also unique in having as its focus the whole of London. Our commitment to taking an overview of London's health services, unfettered by artificial administrative boundaries, has been evident since GLACHC's inception.

There is wide agreement that London has particular characteristics in relation to health care. We make no apologies for seeing London as a special case, though we recognise that intense debate rages about

the ways in which London is special. Some argue that London's historical position as a centre for medical education and specialist acute and high-technology services has led to over-provision. Others, including much of the resident population of London receive the word "over-provision" with a hollow laugh, as they languish on lengthy waiting lists for routine elective surgery, enduring repeated cancellations of admissions and operations, sometimes even after pre-operative medication has been administered.

While few people would deny that a brand-new NHS being designed on a blank canvas would not replicate existing patterns of service delivery, it is plain to London's health service users that the pace of change has brought enormous difficulties to Londoners, and threatens to do so even more in the future. It is also evident that the untrammelled effects of the "market" in health care are likely to lead to chaos and disaster for London if a strategic approach to managing change is not undertaken, a view which has been endorsed by the establishment of a London health enquiry by the Secretary of State for Health.

This working paper takes a user perspective on acute services in London and presents an overview of the situation which is supplemented by Parts 2 and 3, which examine, in some detail, elderly people and single homeless people as users of acute services. It is our contention that these sections illustrate inadequacies in London's acute services which are experienced, to a greater or lesser degree, by many other people who are neither elderly nor homeless. The shortcomings in acute services affect young and old, women and men, people from all ethnic groups and those who are securely housed as well as those who are homeless.

Some people may find it easier to relate to the section on elderly people as at any one time half the beds in the health service are occupied by people aged over sixty-five, and we all may expect to grow old. In fact, the study on single homeless people is no less relevant, particularly as it makes the point that homelessness is not an absolute condition, but rather a spectrum ranging from having secure and adequate housing to having no shelter at all – a particularly meaningful spectrum in London.

What Parts 2 and 3 have in common is that they illustrate the interlinking between physical, emotional and psychological well-being. Also, these sections demonstrate that while it may be administratively convenient to approach acute services as if they were clearly delineated, in fact users know that acute services must be seen as part of a continuum of care which includes primary and community services and continuing care. Users also know that it is fruitless to try to understand their needs by looking only at health services in isolation of social services and domestic support.

It is also an inescapable fact that the population of London – like most capital cities – has factors which require special consideration. London is our largest city, a city with extremes of wealth and poverty. It is a city of immense racial and cultural diversity. Also, its daytime population is increased by those who come to work in it, and who may find themselves as users of the health services.

This inevitably raises questions about who London's health service users actually are. Obviously, CHCs have the greatest contact with their local populations. But London's population could be construed more widely as the sum of those who live or work there, as well as those who gravitate to London in search of work. Looking to the future, it may be that those who work or seek employment in London will come from a wider European catchment area. It is by no means inconceivable that the market in health care will lead to an increase in patients from Paris and Rome, as London's high technology specialities reach out to European markets.

Any blueprint for the future of London's acute services must consider how the resident population is likely to fare alongside other "London users". It is also important to look at "users" as a concept embracing not only present users but also those who wait to be users and those who would be users if the services more adequately met their needs. Indeed, the current preoccupation with those who are actually using the service at the present time has led to an exclusive interest in user satisfaction studies that relate to "hotel services", and quality initiatives that survey those who have already been successful in conquering the obstacle race into existing services.

Throughout our work, it is axiomatic that a user perspective is important. However, perhaps it is necessary to justify this claim. We do not believe that managers, doctors, nurses and other health professionals do not wish to do their best for users. Clearly, most of them do. However, workers of all kinds inevitably have their own vested interests. This is not necessarily a pejorative comment. Managers, in particular, have to try to make things work within parameters that they have not chosen and cannot control. Those who use the service, or try to do so, are concerned primarily with the extent to which it meets their needs. They know whether their distress is exacerbated by long waits, inadequate information, cultural insensitivity or poor treatment.

Purchasers may see themselves as users' friends, but they are inevitably constrained by institutional pressures, loyalty to their or ganisation, and above all by the painful underfunding of the NHS in London. Moreover if purchasers are to look after users' needs, there will be a considerable interval, assuming current rates of progress, before they reflect London's population in terms of race, culture and disability, and clearly they will never do so in terms of age and socioeconomic status. Only users themselves, through a multiplicity of community groups, voluntary organisations and CHCs, can truly express their needs and concerns.

Ros Levenson Director, GLACHC January 1992

EXECUTIVE SUMMARY

This report from the Greater London Association of Community Health Councils (GLACHC) provides a users' perspective on acute health services in London. It begins with an overview of the situation in the capital and proceeds, by considering two vulnerable groups – elderly people and single homeless people, to look in detail at aspects of acute services which are of concern to users in general.

Quality - the user point of view

The issues of equity, access to services, efficiency and economy, social acceptability, effectiveness and relevance to need are all viewed from a users' perspective. The following principal conclusions are drawn.

Equity

Highest priority must be given to achieving equal access to all users. People who present with multiple medical, social and housing needs should not be excluded from receiving the best possible treatment. A comprehensive equal opportunities programme should be established after widespread consultation with community organisations. All staff training should acknowledge the diverse population which uses the health service.

A number of barriers prevent equal access to services. The lack of multilingual staff particularly affects black and minority ethnic people. Disabled people are disadvantaged through poor physical access to buildings. All hospital services should be reviewed and changes made to improve access. The development of services for elderly people that are responsive to the needs of London's racially diverse population is now a priority.

User-centred services

Services should be oriented around convenience to users. Waiting times, particularly in accident and emergency and outpatient departments need to be considerably reduced. Cancellations both of outpatient appointments and inpatient treatment also need to be reduced. Appointments for homeless people should be arranged when they are inpatients since they do not have an address to send the appointment on to.

The cost to people of using the service should be further examined. Users should not have to pay for essential appliances and health benefits, including travel costs, should be made easier to claim. In addition a significant improvement is required in non-emergency patient transport.

Both outpatient and inpatient facilities need to be improved and made more comfortable. A programme needs to be introduced to do this and minimum standards enforced.

Social and emotional support for patients needs to be improved, particularly when assessing for discharge, and when dealing with people in mental distress. Many hospitals do not provide the appropriate environment or personnel for people to receive counselling. There is a particular lack of multilingual and black counsellors available.

There should be a review of the role of accident and emergency departments with a view to developing services that reflect actual patterns of usage rather than the convenience or preferences of service providers. It has to be recognised that in London accident and emergency departments are the main source of primary care for some people, particularly those who are homeless.

Neither acute psychiatric services nor accident and emergency departments provide an appropriate service for people who need emergency psychiatric help. This must be addressed either by the provision of emergency psychiatric clinics or by appropriate staff being permanently available at accident and emergency departments.

In a number of areas users have significant differences with staff over how services should best be provided and organised. Groups representing users should, therefore, be involved in the planning and development of all acute services to make sure that their needs are taken into account.

A system for setting and monitoring quality standards and clinical outcomes, evaluating new procedures, and enhancing clinical audit should be established, involving users at all levels. This should have a powerful remit over both the purchaser and provider functions, from which it should be independent, and involve users through voluntary organisations, CHCs and other groups.

Users' rights

There is a great need for comprehensive information about the range of health services available to residents in a district. This should be in an easily accessible form and cover both primary and acute services. GPs too need better information about what is available and to communicate this to their patients, particularly elderly people who suffer due to the very low expectations of what is a vailable for them.

Health service workers need to recognise that people have a right to negotiate their own care and treatment and where necessary to challenge the suggestions of professionals. People should be assessed for treatment on the basis of their individual condition rather than on criteria such as age.

There are major problems with communication between service providers and users. Elderly and black and minority ethnic people experience particular difficulties in their communication with clinical and nursing staff.

A comprehensive range of patients' rights should be guaranteed, backed up by a more efficient system for complaints and redress. Information about how to make complaints and obtain redress should

be disseminated, thus enabling both users and those working on their behalf to pursue a grievance.

Health authorities should develop clear statements of their policy to carers who often feel undervalued and inappropriately used. Policies should state the rights of carers when dealing with paid service providers. It should be recognised that they are an important resource and have a advocacy role, particularly with disadvantaged groups such as single homeless people.

Seamless care

In order to prevent the further fragmentation of services, and to ensure a close integration of primary, secondary and social care, improved coordination between health authorities, local authorities and family health service authorities (FHSAs) should be introduced. Roles and responsibilities between sectors should be established alongside systems for joint planning and liaison. This is particularly important for groups such as elderly and single homeless people who experience a lot of problems with both admission to, and discharge from, hospital and aftercare.

Existing policies to improve discharge arrangements must be fully implemented and close monitoring of readmission rates introduced. Policies for discharge, and other procedures, should be disseminated to front-line workers. Health professionals need to be aware of the risks of discharging people to hotels, bed and breakfast establishments and other forms of temporary accommodation, and to users' own homes where there is not adequate support available. Assumptions should not be made about social circumstances and family support.

Much more attention needs to be given to rehabilitation and convalescent facilities in London. This is particularly pertinent for people who are homeless or do not have support at home.

The way forward

The overall picture painted by this study is of London's health service under pressure as it tries to cope with a reduction in resources and a range of unplanned cuts in services. Aiming to enhance the quality of acute services against a background of a rapid reduction in resources and major structural change is an illusion. Many of the improvements needed require either long-term stability or additional resources.

In line with the World Health Organisation's (WHO's) Health For All strategy, reducing inequalities in health should become the goal of the NHS in London. In order to achieve this and to provide a better quality service for everyone there is a need for a strategic approach to London's health care which views the capital as a whole and collates the needs of its diverse population.

ABBREVIATIONS

Association for Improvement in the Maternity Services **AIMS ACHCEW** Association of Community Health Councils for England and Wales CHC Community Health Council **CPN** Community psychiatric nurse Consumers for Ethics in Research **CERES** East London Homeless Health Team **HHELP FHSA** Family Health Service Authority **FPA** Family Planning Association **FPC** Family Practitioner Committee GP General practitioner Guy's Hospital Psychiatric Team for Single Homeless **PTSHP** People HPU Homeless Persons Unit **IHSM** Institute of Health Services Management LMC Local Medical Committee LAS London Ambulance Service LHPC London Health Planning Consortium National Association of Citizens Advice Bureaux **NACAB** MIND National Association for Mental Health National Association for the Welfare of Children in NAWCH Hospital National Audit Office NAO **NCT** National Childbirth Trust **TAPS** North East Thames Regional Health Authority Team for Assessment of Psychiatric Services PTS Patient Transport Services **RAWP** Resource Allocation Working Party SHIL Single Homeless in London

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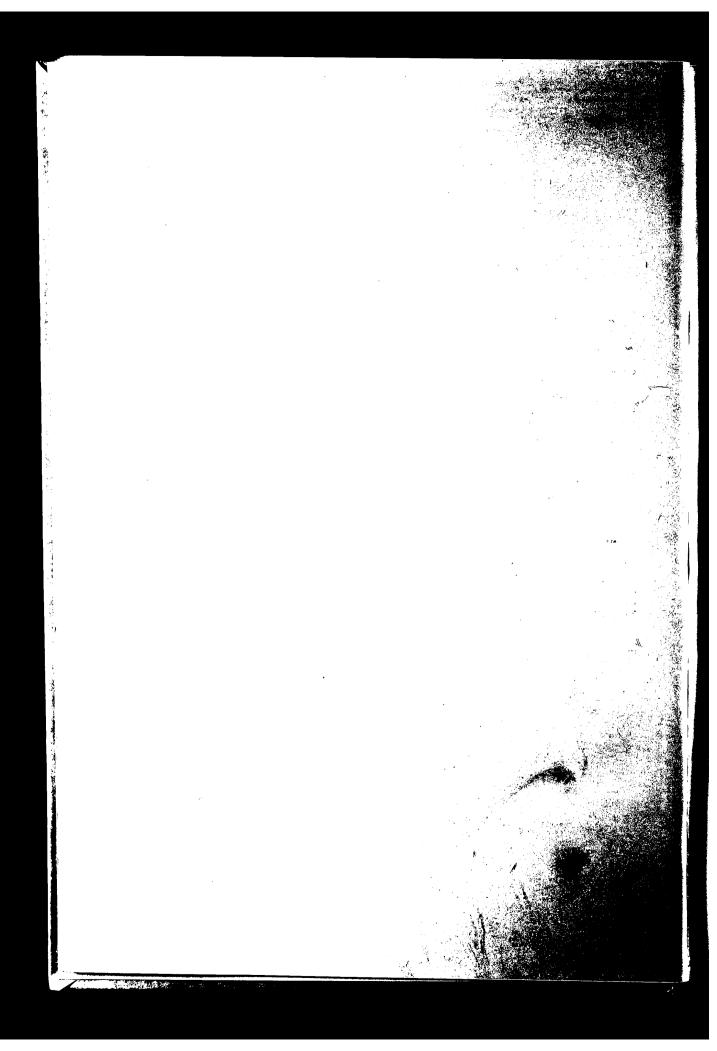
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Part 1

Users and acute services in London



CHAPTER

1

Introduction: The future of health services in London

It has become commonplace in public discussions about the changes occuring in the NHS to find many groups claiming to be acting in the best interests of patients. Yet, despite the rhetoric, no attempt has been made to consult with the public or find out how the people who use the NHS would like to see it improved. In contrast, this working paper starts from a commitment to bring a user and community perspective into the debate about the future of London's health services, by presenting a basic overview of some key issues as seen by CHCs and voluntary groups.

The starting point for this study is a belief that policies for the future of the acute services cannot be artificially separated from other parts of the NHS. A common framework for such an approach already exists in the form of the WHO's strategy for Health for All, which has been endorsed by the UK government and all European states.

The Health for All strategy is based on a number of principles for the development of health policy and services:

- pursuing equality in health and health care;
- reorientating health services towards primary health care;
- encouraging collaboration between different statutory and voluntary organisations;
- promoting public health measures and healthy public policy;
- involving the community in the development of health services.

These commitments are now being applied to the health problems of deprived urban areas through the European Healthy Cities programme, in which Bloomsbury Health Authority and Camden Council are leading participants.

London has special health problems as one of the largest urban areas in Europe, with the inner city containing high concentrations of social deprivation, poverty and unemployment. The Government Office of Population, Census and Surveys has identified inner London as an area with one of the worst levels of overall mortality in the country. In addition, the Black Report in 1980 revealed striking inequalities in health between different occupation classes and social groups, with working class, black and disabled people carrying the heaviest burden of illness and premature death.

The scale of these problems demands that a high priority must be given to reducing avoidable death and illness, and quickly reducing the increasing gap in health status between different groups within the

capital. Acute health services have an important part to play in this process, as they can both help promote good health, and provide treatment for many illnesses. In recent years however, the acute sector has entered a period of crisis and there are increasing doubts about its ability to cope with the challenge it faces.

What are acute services?

For the purposes of this working paper a simple definition will be used: the acute sector includes all hospital-based services, except for the provision of long-term psychiatric services and the chronic care of elderly and disabled people. It thus covers all secondary medical services, including maternity care and acute mental health services, which are often left out of official definitions. This approach has been chosen as it relates to the common experience of "going into hospital" which is not constrained by the sometimes arbitrary divisions between different branches of acute medicine. It also reflects the fact that the concept of "acute care" is poorly understood, whereas nearly everyone has had some experience of hospital.

London's acute sector in crisis

Since the mid-seventies there has been a growing sense of crisis throughout the health service in London. This has been caused by a number of factors. In particular, the impact of the Resource Allocation Working Party (RAWP) formula for redistributing health care resources from London to other parts of the country, combined with general underfunding of the NHS, has led to major reductions in London health authorities' budgets for hospital care. As a consequence there have been heavy cuts in the number of hospital beds and the closure of a wide range of acute services. This has resulted in:

- the closure of many small hospitals and the centralisation of acute services in district general and teaching hospitals;
- longer waiting times for routine operations;
- increasing pressure for patients to stay in hospital for shorter lengths of time and be sent home earlier.

These changes have not occurred in an orderly or controlled way, but have often been the result of piecemeal change, panic measures and short-term thinking, with many health authorities in a state of constant turmoil. In addition, community health and priority services, and local authority social care services, have been unable to cope with the problems caused by the crisis in the hospitals, as they have also been cut back in many parts of the capital.

The cuts in health services have caused suffering for a large number of Londoners, as people have to wait longer to get treated and have worse access to a smaller number of services. Many of these changes have been bitterly resisted by local people, who have campaigned vigorously to protect hospital provision in their area. A

growing feeling of mistrust has spread as health authorities have forced through cuts, so that NHS managers are now seen as no longer sharing the interest of the community.

The situation looks set to deteriorate, with the changes contained in the 1990 NHS and Community Care Act likely to bring about change and major reductions in the acute sector in the capital, especially in inner London.

There is an urgent need to address these issues, by both improving the health of Londoners and the health services they receive. This working paper outlines some of the current problems facing the users of acute services and suggests ways in which the overall quality of hospital care in the capital might be improved.

The study – gaining a user perspective

The study - its aims and how it was carried out

Aims

This working paper aims to set out an agenda for discussion and make some suggestions about the process of developing services and policy. In particular, its aims are:

- to establish a framework for auditing the quality of acute services in London;
- to use this approach to highlight some contemporary issues of importance to CHCs, voluntary groups and users;
- to set out some general recommendations which should be included in the development of policy for the future of acute care in the capital.

At an early stage of the study it was decided that a comprehensive audit of the existing state of London's acute sector as seen by users, was beyond the scope of this paper. It was also felt that it would be inappropriate for any one group to speak on behalf of the diverse range of organisations representing users in London.

Research method

It has not been possible to undertake original research for this section of the study. Instead the working paper has drawn on both formal research studies, and the views and first-hand exeriences of users and the groups which represent them. Where possible, particular problems have been illustrated with both contemporary examples, and empirical evidence.

The background research has involved:

- collecting anecdotes, reports, surveys and research from London CHCs;
- writing to nearly a hundred national and London-based voluntary groups and inviting them to submit a short statement and relevant reports;
- searching the academic literature and health press for research studies and articles;
- organising a series of half-day symposia to gather the views of CHCs and voluntary groups;

- interviewing a few "key informants" with wide experience in this area to pick out important issues;
- extensive discussion amongst the project advisory group, the project consultants and the staff of GLACHC.

During the course of the study it has been surprising to find that relatively little information or primary research exists on users' views of acute care in London. This in itself is significant and perhaps shows how little attention has previously been paid to this subject. Much of the material collected has been from CHCs, voluntary groups and some health authority studies and the evidence is wide-ranging and varies considerably in quality.

Before going on to describe the findings of the study it is important to understand the nature of the information available on users' views.

Information on users' views of health services

In Shirley McIver's recent book An Introduction to Obtaining the Views of Users of Health Services (1991), she briefly discusses the important question of what counts as evidence of users' views and in measuring quality more generally. She notes that most evidence gathered is not, and cannot be, scientific and is sometimes the subject of dispute, particularly with medical staff.

The attempt to establish what will count as evidence for service change lies behind the whole movement to set service standards and ways of monitoring these standards.

(Ibid., p.39)

Traditionally doctors have claimed to know what is best for their patients' welfare, maintaining that this is basically a matter of clinical judgement. Increasingly however, this view is being challenged as both social scientists, and the users of health services themselves, question the basis of many medical decisions.

There is now an influential and growing belief that the experience of health and illness can only be understood as an interaction between the biological processes of the body and the social processes of everyday life (Fitzpatrick *et al.*, 1984). For example, a purely medical model of ill health is insufficient to explain the significant inequalities in health status between different groups, many mental health problems, or the ability of people to recover after trauma. Instead these are best explained as involving social, psychological and emotional processes which cannot simply be reduced to the biophysical mechanisms of medicine.

This is an important point, as a judgement about the quality of health services cannot be made on solely clinical grounds. If a meaningful attempt is going to be made to evaluate health services then evidence of both clinical outcomes, and the views and opinions of users, must be brought together.

To date there have been a number of ways in which information on the views and experiences of users have been collected by either academics, health authorities, or groups representing users. These can be crudely categorised as follows:

- questionnaires and surveys. These are based on the market research principle of asking a sample of people for their opinions. Many CHCs have adopted this method to carry out surveys of local health services, and increasingly health authorities are using routine standarised surveys as an important part of their quality assurance programmes. Whilst questionnaires are relatively easy to use, they are often poorly designed and can end up providing spurious results or relatively little useful information;
- in-depth interviews and discussion groups. The advantage of this method is that it can be much more discriminating in picking up important issues missed by crude questionnaires. It also enables a wider range of issues to be addressed and gives users greater opportunity for raising issues. However, organising interviews is time-consuming and is only normally used in academic studies of specific areas;
- participation through the creation of patient councils, planning forums and advisory groups. A number of health authorities have taken initiatives to involve both users themselves and groups representing and working closely with users in the running and development of services;
- consultation exercises, either with the specific groups representing users or the general public. This is often used as a more formal way of obtaining opinion about the development of policy or major changes in services.

Much of the information available for assessing quality is either based on studies using surveys and questionnaires, which have to be treated with some caution, or is very local and anecdotal. It must also be recognised that there are enormous variations in the pattern of activity and the standard of quality between different health authorities, hospitals, and even wards within the same hospital. It is, therefore, extremely difficult to make generalisations about some issues. For example, in one hospital the quality and presentation of food might be good, whereas in others it is very poor. What is important here is not the average standard of food in London's hospitals, but the fact that it is an area of dissatifaction. The range of variation in quality and the need for minimum standards is an important issue.

In order to overcome some of the difficulties inherent in using survey data and local information, this study has drawn on more rigorous studies, consulted widely with user organiations and CHCs, and used the results of a series of symposia (see Appendix 1) on specific topics. As a consequence the issues identified are of concern throughout London's health services.

The framework and organisation of the study

The starting point for this study is a commitment to improving the quality of acute services for Londoners and ensuring that everyone has

equal access to treatment. In order to achieve this we have chosen to undertake a brief audit of the quality of acute servces in the capital.

A useful framework for assessing quality has been set out by Maxwell (1984) who describes six dimensions of quality in health care. We have used this approach to identify a number of important questions which need to be addressed as part of a quality audit of acute services. These are listed below under Maxwell's six headings:

1 Access to services

A high quality service should ensure that everyone has good access to acute services.

- Is the level of existing provision adequate to ensure good access to services?
- · Are services organised in an accessible way?

2 Efficiency and economy

A high quality service should be easy to use, well-organised and minimise the direct costs involved in receiving treatment.

- How convenient are acute services to use, and do patients get treated quickly and efficiently?
- What are the direct costs to the individual when using acute services?

3 Social acceptability

A high quality service should be sensitive, show respect for everyone as an individual, and give users choice and control over the services they receive.

- Are services easy, comfortable and pleasant to use?
- Are services sensitive to the social needs and cultural values of different groups of users?
- Is enough information given to users?
- What choices are people offered, are their wishes accommodated and their rights respected?

4 Effectiveness

A high quality service should ensure that treatment and care are effective in dealing with all health problems.

- How effective are current medical procedures?
- Are health services organised in such a way to ensure they are effective?

5 Relevance to need

A high quality service should offer a comprehensive range of services and aim to meet the needs of all Londoners.

• How appropriate are acute services to the needs of Londoners?

 How comprehensive are existing services and are there any areas of unmet need?

6 Equity

A high quality service should ensure that everyone is treated equally and has the same opportunity to receive care.

- Is everyone treated equally within the acute sector?
- Do all groups of people have equal opportunities to receive the services they need?

The first three of these dimensions of quality, relating to access, efficiency and acceptability, are discussed in the following chapter on using London's acute services. This examines the experience of going to, staying in, and leaving hospital. The other dimensions, relating to effectiveness, relevance to need and equality are covered in the next two chapters, which attempt to take an overview of the acute sector as a whole. The final part of the study draws some conclusions and sets out some positive suggestions for improving quality and developing policy.

CHAPTER



Using London's acute services

Getting into hospital

In order to identify some of the important issues to users concerning admission to hospital, each of the major routes of entry to hospital will be examined in detail below.

Planned admissions and outpatients

The role of GPs in admission to hospital

Most people only use hospital services after first seeing their GP. It is, therefore, the practice and judgements of GPs which decide whether a patient will go to hospital or not. This may seem a straightforward matter, but a number of studies have highlighted quite significant variations in the referral rates to outpatient departments between different GPs in the same area (Sanders et al., 1989). As a consequence it is suggested that the pattern of GPs' referrals is one of the most important factors in determining the use of acute services. In other words, it is not only the amount of ill health in a community, but also the number of GPs, and the different practices they adopt, which affects how many people are sent to hospital.

London has suffered from relatively poorly developed GP services. The Acheson report (1981), a major study of the state of primary health care in inner London, identified a number of problems, including:

- a high proportion of single-handed GPs;
- a large number of GPs with small list sizes;
- · unsuitable premises;
- · lack of support staff;
- · problems of accessibility and availablity of GPs;
- · lack of co-ordination with hospital services.

An important consequence of poor GP services is the greater use of hospital accident and emergency departments to provide primary health care services (see below). It may also result in higher rates of hospitalisation.

In areas with major social problems the primary care services are less well organised to cope with the extra burdens involved in caring for patients in the community and many more people end up being treated in hospital.

(Acheson, 1981, p.19)

The majority of Londoners are registered with a GP and have reasonably good access to primary medical services, although there are some significant exceptions. In particular, single homeless people often have great difficulty finding a GP who will accept them onto their list (this is explored in detail in Part 3: "Acute care for single homeless people").

In addition, people whose first language is not English can also have major difficulties, either finding out about acute services, registering with a GP or being understood by the doctor. A case in point is the problems which members of the Chinese community in Bloomsbury experience. A CHC/Health Authority survey revealed that:

largely because of the language barrier the Chinese community knew very little about available health service provision.

(Bloomsbury CHC/DHA, 1984, p.7)

They also have difficulty trying to communicate with their GPs, many of whom do not speak Chinese.

Most of these respondents were unable to communicate adequately in English and used sign language or relied on children or other relatives to interpret for them.

(Ibid. p.2)

In recent months there has been some evidence of adverse patient selection, where some GPs have removed certain groups of patients from their lists (Barnet CHC, personal communication, 1991). This has occurred as doctors attempt to meet screening targets establised in the new GP contract. Furthermore, registering with a GP may become more problematic for some people with the introduction of fundholding practices, where GPs can choose to hold a budget for purchasing the bulk of their patients' hospital care. As a consequence, there has become a financial incentive for fundholding GPs either to refuse to take on patients likely to prove "expensive", or to avoid referring them for hospital care. Although there is no evidence that this is happening yet, the Alzheimers Disease Society expressed fears "that budgetholding GPs will be unwilling to refer dementia sufferers to hospital consultants" (letter to GLACHC, April 1991).

When considering the future development of acute services in London, it is vital to examine how the changes currently occurring in General Practice are likely to affect both peoples' access to hospital and the pattern of acute services available. It is too early to predict the dynamics of the new system, which may have a number of unplanned adverse effects on some groups' access to hospital care. The situation needs to be closely monitored to make sure this does not occur.

Outpatients

Once a GP decides that a patient might need further examination or hospital treatment, he or she writes a referral letter to a consultant who holds the outpatient clinic. Until recently GPs were able to refer a patient to any hospital doctor of their choice. Although patients could

not choose which consultant they wished to see, or to avoid, their views were often taken into account by the GP when the referral was made.

Recently, however, as a consequence of the creation of the internal market where care is bought and sold through a series of contracts between purchasers and providers, most GPs are no longer able to do so. Instead the bulk of their referrals now has to fit in with the pattern of contracts negotiated between the local health authority and provider units; only GPs in fundholding practices retain the right to refer wherever they wish. Limited provision has been made by health authorities to enable GPs to retain some choice over referrals by setting aside funds for "extra-contractual referrals". This is a relatively small amount of the total purchasing budget and already there are suggestions that this will be insufficient to allow GPs much freedom.

The length of time which someone will have to wait before an outpatients appointment varies depending on the specialty they need to be sent to, and how urgent their case is. The referral letter sent by the GP will describe the patient's condition and enables the hospital doctor to make a decision about how quickly they need to be seen. Most people who need urgent attention are seen quickly, although one voluntary group has highlighted particular problems that people with asthma experience:

There are times when someone's asthma has deteriorated to an extent where they need to see a specialist again urgently, but are not so ill that they need emergency treatment at casualty. Often they are given an appointment around two weeks later, when they need to see someone sooner.

(National Asthma Campaign, letter to GLACHC, May 1991)

For non-urgent cases people may often have to wait up to six months before going to their first appointment, although there is great variation in the length of wait between different specialties and different hospitals.

Many more people have contact with outpatient than with inpatient services; for every inpatient case treated there are approximately six attendances as outpatients. Yet, according to Bosanquet and Fordham (1987) outpatient services "figure as the most unpopular service provided by the NHS". Outpatient clinics are normally in the district general hospitals, although a few are in smaller hospitals or units.

First contact with outpatient services is through an appointment letter which contains basic information about the time and location of the visit. In a study carried out by Ealing CHC (1989), many people felt that the letter could be significantly improved to include information about likely waiting times, the appointment system and clearer directions about how to get to the clinic. This information is rarely translated into local community languages or available in large format for visually impaired people.

The cancellation of appointments is of concern. In the Ealing CHC study it was found that over a third of patients surveyed had their

appointments postponed or cancelled at least once. This figure varied considerably between clinics and in some specialties reached nearly sixty-five per cent!

Once someone arrives at reception they will often have to wait before they can be seen by a doctor. This aspect of going to outpatients causes a great deal of dissatisfaction amongst users, as it often appears that the appointment system is hard to understand, poorly organised and doctors often arrive late. People can sometimes wait several hours before being seen, often without being told that there will be a delay. The difficulties that this can cause are well illustrated by comments in a CHC visit report:

the waiting times at the Wednesday morning session were also a major problem. Many patients had waited one or two hours, with once again no information as to the cause of the delays. Some of them had had a two-hour wait and then, without seeing a doctor, had to make an appointment to come another time.

(Waltham Forest CHC, 1991)

Long waits also cause problems for patients who are frail, in pain, or have children with them, and are compounded by overcrowded and uncomfortable waiting areas with few amenities.

In addition, access to outpatient services can be difficult for a number of groups. The physical access to some clinics makes it hard for wheelchair users to attend. In a visit to the outpatients department at St Helier Hospital, Merton and Sutton CHC (1991) found a step at the entrance, inaccessible doors, boxes obstructing the corridor and a range of other hazards making entrance for wheelchair users very difficult. The Royal National Institute for the Blind (RNIB) has also commented that many outpatient departments are not responsive to the needs of visually impaired people (RNIB letter to GLACHC, April 1991).

The actual consultation with a doctor can be another area where patients experience problems. In particular, doctors are sometimes hard to understand, the amount of information given about the patient's condition can be inadequate, and the translation of information into other languages is often unavailable.

In a recent survey, the Consumers Association (1991) found that nearly one person in five left their consultation with a specialist without understanding what was wrong with them, and what the treatment was going to be. Furthermore, one in four patients were not given information unless they asked for it. The survey also found that the majority of patients wanted written information to take away with them, yet only ten per cent were given any. Despite this, some eighty-five per cent were satisfied with what they had been told.

In many areas of London a substantial number of people in the local community use languages other than English. For example, in the Ealing study roughly a third of patients attending the outpatient department did not regard English as their first language, and some fifteen per cent said they wanted to use a language other than English to talk to the doctor (Ealing CHC, 1989). Yet eighty per cent of people did not know that the hospital employed a interpreter and only in three

per cent of cases was this service used. In many other hospitals interpreters are not readily available, making communication with doctors almost impossible for some patients. This situation is compounded by the lack of written information available in languages other than English.

The majority of patients going to outpatients with a medical condition do not require admission and will either be referred back to their GP or have to come back to the outpatient clinic for further tests or regular check-ups. In contrast patients requiring surgery will have a planned or "elective" admission to a hospital ward. There are normally waiting lists for elective surgical admissions which vary according to how serious the condition is and the type of operation required.

Waiting lists

One of the biggest complaints about the NHS is that care is rationed by patients having to wait for certain kinds of treatment. In March 1990 over 912,000 people were on hospital waiting lists in England and Wales for either day surgery or inpatient treatment, with roughly thirty per cent of people in the four Thames regions waiting for over one year. In nearly all cases, patients requiring urgent surgery will not have to wait long, but if a condition is not life-threatening or is relatively minor, people can wait up to two years before undergoing an operation.

Overall, the length of waiting lists reflects the level of resources, the number of beds and operating theatres available, and the number of surgeons working in a given area. However, a more detailed understanding is extremely difficult to obtain. John Yates, until recently the Department of Health's adviser on waiting lists, has argued that no single explanation is adequate to explain the length of lists or the variation in lists between districts (Yates, 1987). This has led some managers to claim that waiting lists are irrelevant as they are too flawed a measure of unmet need. However, this argument cannot be sustained, as Yates points out:

The claim that waiting lists are inaccurate is justified to the extent that it is technically true, but there is no justification for using such an argument for failing to act on behalf of the thousands who are waiting far too long in pain and suffering.

(Ibid., p.63)

One way of trying to reduce waiting lists would be to increase the number of people treated per hospital each year. This has been a growing trend over the last forty years, as patients are kept in hospital for steadily decreasing lengths of time. The sharp decrease in the length of stay and the consequent increase in "throughput", also reflects the fact that acute services are having to be used much more intensively as the total number of acute beds has been significantly reduced.

This pressure on resources and the need to increase throughput has been greatest in London, as, relatively speaking, it has lost the largest proportion of hospitals and beds. Although much of this reduction was predicted as part of the shift of NHS resources away from the capital,

it is disturbing that the rate of reduction and the total number of beds lost has been very much greater than planned. A report by the Chairs of Inner London Health Authorities (King's Fund, 1987a) illustrates this clearly:

- Regional plans for the period 1983–93 had assumed a fifteen per cent decrease in hospital admissions in inner London, but actually had a two-and-a-half per cent increase in admissions between 1983–87.
- 1100 local acute beds, representing seventy-four per cent of the planned ten-year bed reductions, have been closed in the first two years of the strategic period.

The picture since 1987 has only worsened, and one of the most recent surveys (GLACHC, 1991a) found that further significant cuts in bed numbers and in elective surgery are still being planned by many London health authorities.

A comparison of London waiting list figures between 1986 and 1990 shows that the total number of people on waiting lists for most of the surgical specialties, has increased substantially (College of Health, 1987; Rigge, 1991). Overall the percentage of people waiting over one year for an operation has been reduced slightly, but this is more than offset by the increase in the number of people on the list. As a consequence, it appears that the number of Londoners waiting over a year for NHS elective surgery has been increasing.

A major consequence of long NHS waiting lists has been the very significant increase in the use of private health care in London and the South East. Research has demonstrated that the most significant reason that people use the private sector is the perceived problems in the NHS, and in particular the length of waiting lists (Cant, 1990).

The focus of private hospital services is elective surgery for conditions such as hip replacements, sterilisation, hysterectomy and varicose veins. In a national study, carried out in 1981, it was estimated that roughly thirteen per cent of all elective surgery was undertaken privately in either independent hospitals or NHS pay beds (Nicholl *et al.*, 1984). This included twenty-six per cent of all hip replacements, and twenty-three per cent of varicose vein surgery. These figures are now likely to be considerable underestimates, as private sector activity nationally has since expanded by nearly thirty per cent (Higgins, 1988).

The availability and use of private health care also varies enormously from one part of the country to another, with the four Thames regional health authorities (RHAs) containing over half of all private acute beds in England (Mohan and Woods, 1985). In South West Thames Region, for example, some fourteen per cent of the population have private health insurance (Ibid.). During the 1980s there was a large increase in private hospitals and beds in the capital (Griffith et al., 1985). This already quite significant private sector activity in London looks set to expand further, with the creation of NHS Trust hospitals, many of which are depending on an increase in private work (Sherman, 1991).

This is a disturbing picture, as the sharp reduction in the number of local NHS acute beds has coincided with a substantial increase in the

number of private hospitals and beds in the capital. During the same period as NHS waiting lists for elective surgery in London have increased, it appears that the amount of privately performed operations has risen sharply.

If the NHS has not been able to cope with the increased demand for routine surgical operations, then it looks as if the private sector has benefited from this unmet need. This is apparent when statistics for abortions are examined. In 1985 the number of NHS abortions in the four Thames regions was 22,643 and by 1989 this had risen by nine per cent to 24,622. In contrast privately performed abortions had increased by roughly thirty-seven per cent from 31,330 to 43,011 (Labour Research Department, 1991). This change is largely a result of the NHS failing to keep pace with demand, as the Family Planning Association (FPA) points out:

Although most women would prefer an NHS abortion many seek the operation elsewhere for a prompter and more efficient service.

(Letter to GLACHC, April 1991)

In a recent seminar at the London School of Hygiene and Tropical Medicine, Nick Black cited figures from Sheffield University which showed that thirty-five per cent of elective surgery in the North West Thames Region is now carried out privately.

It is difficult to draw firm conclusions about this apparent shift from NHS to private elective surgery from the limited information available. However, it is quite likely that many people, when told how long they might have to wait for an NHS operation, go straight to the private sector. As a consequence, their need for an operation is not recorded in London NHS waiting list statistics, which therefore may be a considerable underestimate of unmet need.

The failure of the NHS to provide a comprehensive range of routine surgery appears to be on the verge of becoming official policy. The North East Thames RHA has been considering restricting waiting lists for varicose veins, and a number of minor operations, to those people with a serious clinical need. Alarm has also been expressed about the failure of a number of health authorities in London to meet their statutory obligations to provide comprehensive family planning services. A recent national survey by the BBC (FPA News Release 26.3.91) revealed that one in five health authorities, including a number in London, were refusing to carry out routine sterilisation operations in order to save money. This has led to "couples being forced to pay for the operation".

Presumably, people who are not allowed on the waiting list or whose health authority has ceased to offer certain operations will be expected to pay privately. Any further moves from NHS to private surgery will certainly result in considerable inequalities in access to these basic services, as the majority of Londoners are unable to afford private health care.

Non-emergency transport to hospital

The majority of people using outpatients or being admitted to a ward for planned surgery are able to make their own way to hospital.

However, this is not always a straightforward matter. Over the last twenty years, with the centralisation of acute services and accident and emergency departments in large general hospitals, patients now have to travel considerably further than in the past. Although inner London hospitals are relatively close together, the transport problems of the capital mean that getting to hospital can often take a long time and this is particularly difficult for parents taking children to hospital'and for frail and disabled people.

People who are severely disabled or seriously ill (and defined as "medically unfit") depend on the non-emergency ambulance service to get to hospital. A recent study of non-emergency patient transport in London concluded that:

London Ambulance Service's (LAS) capacity to bring in and take home the number of patients requested within the criterion of medical unfitness, as currently understood, is broadly satisfactory.

(Fogarty, 1987, p.38)

However, the report goes on to point out that this has only been possible because the "goalposts have been moved" so that:

in all four divisions the number of walking patients accepted as qualifying under the criterion of medical unfitness has been sharply reduced.

(Ibid.)

As a consequence:

over half a million patient journeys which two or three years ago would have been carried out by the LAS have now to be made by other means.

In other words the service for people with impaired mobility has deteriorated significantly.

In addition the quality of the LAS' non-emergency transport was found to have a number of serious shortcomings, including problems with punctuality for appointments, prompt collection and return home, or excessively long journey times for elderly or frail patients.

Since the report, non-emergency Patient Transport Services (PTS) have been reduced after the LAS budget for 1990–91 included a three-and-a-half per cent cut in this area. In an attempt to reduce demand, policy was also changed in September 1990, so that blind people and other groups of walking patients no longer receive transport to hospital. Evidence of a high and increasing number of cancellations was also revealed in an answer to a pariamentary question (Monday 29 October, P.Q. 5089 1989–90); the number of patient journeys cancelled between June and September 1990 rose from four thousand to seven thousand per month.

The most recent survey carried out by GLACHC in February 1991, revealed that all CHCs which responded were receiving complaints about the service, the number of complaints was increasing, and there were many examples of people having difficulty getting ambulance transport to day hospitals (GLACHC, 1991b).

The misery and distress caused by the change in policy and increasing numbers of cancellations and delays is clearly illustrated by

a report from Newham CHC (1991) on the non-emergency service in its district, where it gives over twenty examples of serious problems, including:

A severely arthritic patient with Parkinson's Disease has missed three consecutive outpatients appointments due to lack of transport. An ambulance did arrive on two of the three occasions — only to inform the patient that there was no space in the ambulance for him and no further ambulance could take him to hospital that day.

(Ibid.)

In addition to problems getting to hospital, a study by Wandsworth CHC (1989) revealed that the late arrival of patients to the outpatient department increased the time people had to wait or meant that some patients actually missed the doctor. The feeling of many groups is illustrated by Wandsworth CHC's comment:

All the elderly patients we spoke to were full of praise for the ambulance staff. Some had noticed a deterioration in the service and were very anxious about the future. The overwhelming impression was of helplessness — "we must not complain", "it's not so bad", "what can we do", "we will get by" — a situation with which no-one should be proud of or satisfied.

(Ibid., p.6)

One consequence of the deteriorating ambulance service is that increasing numbers of people are using taxis to get to hospital.

We were disconcerted to learn that two people we spoke to had come to the hospital by taxi because public transport would have been too difficult for them. One of them had a full leg plaster, but neither had been offered an ambulance.

(Redbridge CHC, 26.2.91)

Not only is it worrying that the service is unable to help this type of patient get to hospital, but it means the sometimes heavy costs of getting to hospital are being met by patients. Although people on benefits and low incomes are able to meet these costs through the Health Benefits Scheme there is evidence that many people who qualify for assistance either do not know they are eligible or find it too difficult to claim. A review of the workings of health benefits by the National Association of Citizens Advice Bureaux (NACAB, 1991) concluded that:

The evidence received from bureaux suggests that large numbers of persons who would be entitled to help with NHS charges do not claim because of ignorance of the arrangements for help and the complexity of those arrangements. In addition the increasing shortfall between benefit levels and NHS charges is causing considerable hardship to people on low incomes and may deter people from getting the health care they need.

Cancelled admissions

A major inconvenience many patients face is having their admission cancelled, often at the last minute. Up to one in ten planned surgical

admissions is cancelled in the Thames regions, with some districts having very high cancellation rates. For example, Hammersmith Hospital cancels one in five planned admissions.

Whilst pressure on resources may mean that a substantial number of cancellations is inevitable, there is much more that could be done to ensure that those least able to cope with cancellations, such as elderly people, do not have their operations cancelled. The threat of cancellation now means that in some hospitals patients have to wait until the last minute to confirm they can come in, leaving potential patients on tenterhooks. In the worst cases, operations are cancelled at the very last minute, after patients have been admitted and given pre-operative medication! (Barnet CHC, personal communication, 1991). Hospitals should therefore make every effort to ensure that cancellation rates are reduced and that adequate warning is given to patients.

Emergency admissions to hospital

Calling an ambulance in an emergency

In addition to its non-emergency work the LAS provides an emergency service to some 9.5 million people, including visitors and commuters. In the last few years the LAS has been the subject of controversy, following the ambulance workers' dispute and a major restructuring of its management and organisation. In general, a high quality emergency service continues to be provided, with few complaints being received by CHCs about excessive delays. Despite this, there is still considerable room for improvement.

Government targets for the 999 emergency service state that in ninety-five per cent of all calls an ambulance must be on the scene within fourteen minutes of contact being made with the control service. However, in recent years the LAS has failed to reach this target, so that in the first half of 1989 only seventy-eight per cent of calls were responded to within fourteen minutes (LAS panel agenda, 20 Sept, 1989; quoted in NUPE, 1990). In a study of NHS patient transport conducted by the National Audit Ofice it was confirmed that London has one of the worst response times in the country. The major problems with transport in the capital obviously hinder the effectiveness of the service, but it is important that the service should be developed to enable this target to be reached in the near future.

Referral from a GP

The major issue for users about emergency referral to hospital by a GP, is access to a doctor at night. In some parts of inner London, heavy use is made of deputising services, which can often lead to delays in a patient being seen and the doctor having far less knowledge of a person's medical history.

The accident and emergency department

Before the foundation of the NHS and the expansion of free primary health care, "casualty departments" served as open-door facilities providing immediate necessary treatment to people without the means to pay for a doctor. For many people, and particularly for single

homeless people, this function has remained essentially unchanged. The official function of casualty has in the meantime gradually shifted towards providing a more specialised emergency service, reflected by the change in name from "casualty" to "accident and emergency" department.

Accident and emergency departments have a distinct pattern of use in urban areas, compared with rural and suburban districts. In many London hospitals only about twenty per cent of people attending the accident and emergency department are seriously ill or are suffering from major injuries. The rest of the people attending have a wide range of relatively minor problems with about thirty per cent of people returning for follow-up visits (Institute of Health Services Management (IHSM)/ACHCEW, undated). This had led to a view that accident and emergency services are being inappropriately used and that many problems should be dealt with by GPs. There are a number of different reasons for the high use of accident and emergency facilities by people with minor problems, but important amongst them is the relatively poor access which some people have to GPs in inner London, especially at night. This is particularly true for single homeless people.

Despite attempts to re-educate the public about the official use of accident and emergency departments the "problem" of inappropriate attenders has persisted. It has been suggested that accident and emergency departments should rethink, or come to terms with their function as a primary health care provider "and make specific arrangements for fulfilling it, rather than to try and resist established local preferences" (British Medical Journal, 1978).

In recent years, with the closure and centralisation of a number of accident and emergency departments, there has been increasing pressure on many emergency services in inner London. In a survey of consultants in accident and emergency units carried out in 1990, just over sixty per cent said that they were "experiencing difficulties in providing casualty care for their patients" (Francome, 1990).

Many of the issues which are raised by people using accident and emergency services are similar to those mentioned above when discussing outpatient departments. Physical access to the accident and emergency department can be problematic, particularly for disabled people, with poor car parking nearby, and inadequate signposting.

The external signs to A&E are not clear and are hardly visible in poor light ... There is inadequate parking space for patients who may have a mobility problem ... This is compounded by the uneven and cracked paving stones on the walkway to the department.

(Waltham Forest CHC, 1990)

Once inside, the waiting area can be spartan. A commonly mentioned problem is the lack of toys for children and facilities for feeding and changing babies.

Of particular concern is the length of time people sometimes have to wait before they are assessed by a casualty officer. In a survey of the accident and emergency department at the London Hospital,

Tower Hamlets CHC (1990) found that people often had to wait over two hours and on occasion up to four hours. Similarly, at Whipps Cross accident and emergency department some people waited over six hours before being properly examined (Waltham Forest CHC, 1990).

It also appears that long waits are made more frustrating as people are often not told how long they might have to wait:

Patients commented that once in the area they felt forgotten and would have wished for a member of staff to inform them of the progress of their admission.

(Ibid., p.3)

A number of CHCs have commented that patients feel that staff are too busy, which results in people feeling unable to ask for other sorts of information. Written information materials in accident and emergency departments are not always available and are rarely translated into languages other than English.

The lack of multilingual staff or interpreters was raised as a particular issue in the GLACHC symposium on black people and acute care. This can make communication between medical staff and patients very difficult.

A significant number of people using accident and emergency services are in an emotionally or mentally distressed state, as a result of trauma, violence or a mental health crisis. It is therefore important that counselling and other services offering emotional support are easily available and that users have a choice of crisis provision. At present these supports appear to be poorly provided in London hospitals.

The experience of being in hospital

A high quality health service must be able to treat people as individuals. In order to do this, it is essential to both recognise, and be responsive to, the many ways in which users are different. These include differences in peoples':

- health status varying from healthy to chronically ill;
- age, sex, race, sexual orientation and physical ability;
- culture and values;
- domestic circumstances and responsibilities:
- · need for support when suffering pain, or facing death or disability;
- · level of emotional support available from family and friends;
- ability to understand, especially if distressed or confused;
- · dependency on medical care;
- frequency of use of acute services.

Some people using acute services are completely healthy, such as an expectant mother; other users will be dependent on medical care for

the rest of their lives. Both categories should receive care which takes these differences into account and treats them with dignity and respect.

In general, most people appear to be happy with their experience of going into hospital (Social and Community Planning Research, 1988). However, despite this high level of overall satisfaction with inpatient hospital care, there are a number of aspects of life in hospital which are a cause of dissatisfaction to patients (Jones *et al.*, 1987). These areas of discontent have consistently featured in national surveys during the last thirty years, and this still appears to be the case in London today.

The findings of detailed work on patient satisfaction (Thompson, 1989; Thompson, personal communication, May 1991) suggests that there are two distinct components which shape peoples' views of staying in hospital. The first is the "hotel services" and the physical environment, which are generally a source of dissatisfaction and the area of greatest variation from one ward to another. The second is associated with the care, treatment and information which patients receive. The human face of life as an inpatient, especially nursing care, is the source of peoples' general satisfaction with staying in hospital. However, important aspects of the clinical relationship between doctor and patient are more problematic.

The context of care – the hospital environment, "hotel services" and life on the ward

When different hospitals, and wards within hospitals, are compared using standard questionnaires, there is a surprisingly large variation in levels of patient satisfaction with environmental factors and hotel services, such as food (Thompson, 1989). As a consequence it is hard to make generalisations which can be applied to all hospitals in London. Instead, it is more appropriate to briefly identify the main areas which consistently show up as causing dissatisfaction in both London-based and national studies.

The hospital environment

A common impression of walking into many London hospitals is of poorly maintained old buildings in need of a great deal of repair. The poor state of the fabric of hospital buildings is often reported in CHC hospital visit reports sent to GLACHC. For example:

Generally tatty with worn baths, cracked floors, peeling paint, taped-up windows, etc.

(Merton and Sutton CHC, 1990)

Paint was peeling off in large lumps and on one ward there was a large crack which seemed to go right through the wall and appeared to be dangerous.

(Ibid.)

Major London hospital sites are very large, complex and hard to get around, making entry difficult for many people. Signposting is often inadequate and rarely translated into local community languages, and the physical access into and within many buildings is often poor, causing difficulties for people with impaired mobility or for those who use wheelchairs.

This situation is well illustated in a CHC report on access to Sutton Hospital:

As the main entrance is completely inaccessible for someone in a wheelchair it is neccessary for people to use the side entrance... Here the two doors open outwards... There is another set of double doors inside to which the same applies. This entrance is not sign-posted as an entrance for people with disabilities and there is no receptionist permanently placed inside to help anyone find their way, or gain access through the doors.

(Merton and Sutton CHC, 1991a)

Once in hospital there can be many obstacles for people with mobility impairments, including flights of stairs, small lifts, equipment filling corridors, and furniture blocking wards. Comments made in a seminar on access to hospitals describe a common situation:

In many new hospitals it is still a question of the disabled person being unable to get into a ward bed. Rooms are cluttered with chairs and equipment and furniture has often had to be removed before she could get into the ward. The beds are often too high or too low...

(Centre on Environment for the Handicapped, 1987)

"Hotel services" and life on the ward

The major sources of inpatients' dissatisfaction which have been consistently demonstrated in satisfaction studies and CHC visits include:

• Ward routine: The rigid ward routines still operating in many hospitals remain a major cause of complaint amongst inpatients (Jones *et al.*, 1987). People are still routinely woken before 7 am and may have to wait over an hour before being given breakfast. If someone is in pain or has had a poor night's sleep, this can be particularly frustrating.

As Jones et al. remark:

Ward routine is invariably given as the reason for this practice, but it is a remarkably inflexible system that cannot be rethought after twenty-four years of adverse comments by patients.

(Ibid.)

Visiting hours are also restricted in some London hospitals, although over sixty per cent of hospitals in the Thames Regions appear to have liberal policies which allow over five hours a day for visits (Griffith, 1988). National figures have shown that roughly one in five patients feel that visiting hours are too inflexible for the convenience of the people coming to see them (Thompson, 1989). This is despite a government committee recommending, as long ago as 1976, that there should be flexible visiting arrangements over an extended period. Given that many hospitals now operate "open" visiting hours there seems no convincing reason why much longer visiting hours cannot be adopted in all London hospitals.

• Facilities: The low quality of cleanliness on some wards has been noted in a number of London CHC visit reports. Barnet CHC (1990a) found:

ingrained dirt on the window ledges, at least two weeks' dust under the radiators, on the floor and pipes and the insides of empty lockers, obviously unwashed...

In addition, washing and toilet facilities receive adverse comments. For example, the poor state of the showers on one ward was described in a visit report as "mouldy and rusty with condensation". Although cleanliness is not a problem in the majority of wards, it is disturbing to find it raised as an issue in even a few cases. In addition, there are few wards with appropriate washing facilities, such as showers, as required by Muslims.

Of more general concern is the lack of facilities on many wards which can be easily used by disabled people – in particular, many bathrooms are not designed for wheelchair use. London CHCs report many examples of toilets which cannot be used from a wheelchair, and inaccessible washing facilities, including steps down to the shower, no low mirror or coathooks, and completely inaccessible baths.

The noise level in hospital can also be disturbingly high, whether caused by traffic, the television or other patients. Overall some ten per cent of patients nationally find noise a nuisance with it often causing sleep problems (Thompson, 1989). Similarly the temperature control and ventilation of wards is often inadequate, with just over a quarter of people reporting that the ward was too warm and nearly forty per cent feeling that it had too little ventilation (ibid.).

• Food: In contemporary folklore, hospital food, like school meals, is legendary for its poor quality. Sadly this popular notion is confirmed by patient satisfaction studies which reveal that only twenty per cent of inpatients believe that the "quality of the food was very good" and just over half feeling that the food was not hot enough (Thompson, 1989). CHC visit reports tend to confirm this picture:

The questionnaire showed the main dissatisfaction to be food – portions not enough for the often voracious appetite of the newly delivered!

(Merton and Sutton CHC, 1990)

Of particular importance is the lack of choice, with only a quarter of inpatients being asked how much food they wish to eat and about the same number being given no choice of menu (Thompson, 1989). Catering for the needs of people from a range of cultures or with different beliefs is particularly poor. A number of London CHCs have confirmed this in their districts and have commented that the situation is often compounded by the lack of staff able to speak local community languages and the limited availablity of information about the choices available, or how food was prepared. It is also disappointing that a large number of hospitals still don't have a healthy food policy.

• Amenities and privacy: Good amentities are an important part of inpatient life, as boredom can often occur when confined in hospital. Despite this obvious need it is clear that some London hospitals still fail to provide patients with many basic amenities. Nearly all wards provide access to the television and radio, but far fewer offer a good range of newspapers and reading materials, or provide no-smoking areas and quiet rooms without television.

Ward amenities are often inaccessible, for example CHCs have reported that the telephone and drinks machine on some wards are placed too high to be used from a wheelchair. In addition, mobility around the ward is made difficult by the large number of obstacles, including fixed chairs. The lack of appropriate furniture on many wards is another problem, for example chairs are often all the same height causing difficulties for people who need either lower or higher chairs.

Lack of privacy is another common experience, with nearly half of inpatients nationally not having access to a private room for confidential discussion. Merton CHC illustrates the problems this can cause in a visit to one ward in St Helier hospital:

If relatives needed comforting there was nowhere for that purpose other than the sister's office which is hardly private.

(Merton and Sutton CHC, 1990)

Yet in a study at the Royal Marsden Hospital (Thompson, 1989) three-quarters of patients who had access to this facility found it useful.

Although the issues listed above are often minor in nature, when taken together they can result in the overall quality of life in some wards being very poor. This neither helps make the stay in hospital enjoyable nor aids recovery. For patients who are dependent on medical care, who use services regularly, or have reasonably long stays, these problems are of particular concern.

The overall picture painted by CHC visits and patient satisfaction work is one of great variation from hospital to hospital, and from ward to ward. However, it seems reasonable to suggest that there is probably room for making improvements in many of the areas outlined above in nearly every London hospital. In order to achieve this, routine ways of monitoring the quality of this aspect of care should be established, allowing minimum standards to be ensured.

The content of care - support, information and choice

The majority of people in hospital feel out of control (Social and Community Planning Research, 1988) and are often scared, vulnerable and in a dependent state. It is therefore important that throughout their stay patients are well supported, kept informed, always respected as individuals and given as much choice and control over their treatment as they wish.

Patient satisfaction studies have indicated that the content of care is highly rated. However, there seems to be a distinction between satisfaction with the actual process of care and treatment, and the

amount of information and choice which patients are given (Thompson, 1989).

The care and support of patients

The majority of hospital care is provided by nurses, who help administer treatment, and provide basic services and support to patients. In general, the quality of nursing is regarded very highly by patients, although, as detailed in the section on elderly people, CHCs do receive complaints about specific aspects of nursing care.

One area of particular concern, which has been identified by a number of CHCs, is the shortage of nursing staff and the use of agency nurses.

The only complaint voiced by patients and their visitors, particularly in Dickens Ward, was the constant use of agency nurses, and the feeling of insecurity this brought in its wake. Also that the day staff were very busy and did not have time...

(Harrow CHC, 1990)

With increasing pressure on resources and continuing problems in the recruitment and retention of nursing staff, these experiences are likely to become increasingly commonplace. This is a worrying development as it is important to ensure that all inpatients receive a high standard of care and good social and emotional support during their stay. Although there is no evidence that standards of care are being seriously undermined by staff shortages, comments from CHCs suggest that the emotional and social support which nurses provide is suffering as staff have less time to talk to patients.

The importance of support in coping with the emotional distress caused by physical illness is beginning to be recognised (Wortman and Conway, 1985). In a number of research projects it has been demonstrated that adaptation and recovery from illness is helped by patients being given social support (Broadhead *et al.*, 1983).

There are several potential sources of support for a patient including family and friends, nurses and other ward staff, and staff whose role it is to support patients, such as social workers and counsellors. As mentioned above, visiting hours can be inflexible making access to family and friends difficult, particularly if the hospital is some distance from the patient's home. This situation could become more common if patients have to travel further when health authorities place contracts with more distant hospitals.

Ideally each patient should be asked if they need practical help, for example with their domestic responsibilities, or if they would like to talk to someone about their illness. Hospital social workers play an important role in supporting people with their domestic responsibilities and other problems, and it is of concern that social work services are being cut back in many London hospitals.

Most patients are happy to be supported by talking to nurses. The availability of professional counselling services is, however, particularly important for people undergoing a mental health crisis, for patients who have suddenly become seriously disabled, for people who realise

they have a degenerative condition, and for those who face death. Good counselling services are now available in specialist units dealing with people suffering from cancer or from HIV/AIDS. However, outside these few particular areas counselling is patchy and not widely available.

In the GLACHC symposium on black people and the acute sector, the need for support from staff speaking appropriate languages was highlighted, and the lack of black counselling services was identified as an important unmet need.

Information and choice about treatment and care

High quality acute care should aim to be "patient-centred", where services and procedures are developed with the needs and wishes of users as a guiding principle. Central to this approach is the idea of a partnership between medical staff and patients which enables people to be involved in important choices about their own care. This can have many benefits, as it helps improve users' confidence, leads to a greater trust between patients and staff, and may help treatment. According to a study carried out in King's College Hospital:

Patients recover better and faster when professional staff regard them as partners in their own care.

(Therapy Weekly, 1989)

The key to building a successful partnership between users and staff depends on ensuring that:

- patients are kept well informed;
- the full range of available choices about treatment is explained;
- patients are fully involved in decisions about their care and treatment;
- everyone is treated equally and has their rights respected at all times.

The extent to which each of these preconditions is met in London's hospitals will be examined later, and important issues and areas in need of improvement will be identified.

Information to users

Unlike aspects of the context of care mentioned above, which can vary considerably from hospital to hospital, patients' dissatisfaction with the lack of information about their illness and treatment is a constantly reported complaint (Jones *et al.*, 1987; Thompson, 1989). National surveys have consistently shown lack of information as one of the most important sources of discontent with acute care. As might be expected, people suffering from a chronic medical condition are especially likely to require information. For example, a survey found that ninety-five per cent of people with multiple sclerosis wanted more information.

In the review "Informing health consumers", Kempson (1987) outlines some of the reasons why patients lack information:

• doctors only spend about five per cent of the consultation time conveying information;

- patients forget at least half of the information they are given during a consultation;
- many patients cannot understand medical jargon and have only a limited knowledge of most illnesses and therapies;

Although, as Kempson observes:

Low levels of patient knowledge, by themselves, are unlikely to cause a breakdown in communication, if doctors are fully aware of them. It has been shown, however, that house doctors wrongly predicted the knowledge of patients in forty per cent of cases. They tended to underestimate their knowlege of the illness and overestimate their level of knowledge of surgery.

(Ibid., p.10)

One solution to the problem of poor communication would be for patients to ask more questions, as research has shown that unless staff are asked for information it is unlikely to be volunteered. Despite this, there is ample evidence that many patients do not like to ask doctors or nurses, either because they seem too busy or because they don't have the opportunity or privacy.

Studies by a number of London CHCs and health authorities have highlighted the inadequacy of the information given to patients and problems with communication between patients and staff. In particular, major problems are caused by the failure of health services to make information accessible to people whose first language is not English.

In a report of the health care needs of Chinese people living in Bloomsbury a number of problems with communication were identified, including the lack of enough Chinese-speaking staff or translators. This led to several people commenting on apparent misunderstanding and confusion about the purpose of the treatment they had received in hospital:

No-one from the hospital explained to me about my illness or told me how to look after myself after the operation. Hospital staff lacked patience or time to explain.

(Bloomsbury CHC/DHA, 1984, p.22)

A similar picure was painted in a survey of Bengali women's experiences of having a baby at University College Hospital which concluded that:

Most of the women felt that they could neither ask the questions they wanted to nor have things explained properly to them. This was because there were too few interpreters...

(O'Keefe, 1984, p.2)

Although these particular situations may have improved, recent comments from CHCs confirm that these problems are still very common throughout the capital.

Another important group whose needs for information are not taken properly into account are sensory-impaired people, whether

they are visually impaired, or deaf. Staff who can use sign language are rarely available in hospitals and most information is inaccessible for people who are blind or visually impaired.

Acute hospitals often need to transmit written information to visually impaired patients and there has to date been little work undertaken on making this information accessible to the visually impaired.

(Royal National Institute for the Blind, letter to GLACHC, April 1991)

There are important benefits to be gained from keeping patients well informed, as a recent review demonstrated. Patients who received information pre-operatively are less anxious, suffer fewer post-operative complications and have a faster convalescence than those who did not receive information (Morris *et al.*, 1989). There is also some evidence to suggest that pre-operative and post-operative visiting of patients to give them information and help them prepare for surgery, can assist a faster recovery (Thompson, 1990).

Choice and consent to treatment

Information, whilst essential, does not in itself ensure that people understand, or are involved in, important decisions about their care. This requires careful explanation of all the choices available and a willingness by medical staff to take users' opinions fully into account.

As the NHS Management Executive's Guide to consent for examination or treatment (undated) makes clear:

Patients are entitled to receive sufficient information in a way that they can understand about the proposed treatment, the possible alternatives and any substantial risks, so that they can make a balanced judgement.

One of the ways in which this principle is put into practice is the use of signed consent forms to make sure that patients are not forced to undergo treatment against their will. This is a legal necessity for all surgical procedures and for the majority of clinical research trials. However, there is evidence that signing a consent form does not necessarily mean that a patient understands the treatment he or she will receive. A study of patients' knowledge of treatment when giving written consent found that out of one hundred people after an operation, twenty-seven did not know which organ was operated on and forty-four were unaware of the exact nature of the surgical procedure. (Byrne et al., 1988). There are probably many factors which lead to some patients' poor understanding of treatment, but almost certainly this reflects the issue raised above: people are not given enough information about their illness or treatment in a way that they can understand or remember.

In order for patients to be involved in their care they must also be given information about alternative forms of treatment and different choices which might be available. However, it appears that in certain areas professionals are reluctant to offer users the full range of available choices. According to the Association for Improvement in the Maternity Services (AIMS) this is a common occurrence:

SEASON PROPERTY.

All too often women are only given the choices, about how to have their baby, which are approved of by the obstetricians and midwives. The option of having a home birth or DOMINO is rarely discussed, unless it is raised by the woman first. Every woman should also have access to hospital statistics giving her information about outcomes.

(AIMS, letter to GLACHC, May 1991)

As information resources are being developed, staff should work closely with groups representing users to make sure that people will be given enough accessible information to enable them to be fully informed about all practical choices.

Wider use of advocacy should be given serious consideration. It needs to be acknowledged that staff employed by hospitals cannot be true advocates for users. Extra funding is often required to enable local independent advocacy workers to provide a comprehensive service.

There are a number of ways in which users' lack of information about their illness and treatment could be addressed by health authorities and staff, including:

- staff devoting more time to explaining about a patient's condition and the treatment he or she might receive;
- better training of members of staff to help them appreciate the importance of keeping patients well informed, and to improve their communication skills;
- producing a comprehensive range of information materials including leaflets and videos. These are still only widely available in a minority of hospitals. It is important that they are presented in an accessible way and are translated into major community languages;
- the employment of more staff from black and minority ethnic communities and the provision of interpreting services, to help improve communication with users whose first language is not English.

Equal treatment and patients' rights

The goal of ensuring equal treatment in health care has been an important principle since the inception of the NHS. Yet there is considerable evidence that the basic rights of a number of groups of users of acute services are either consistently ignored or have never been properly established. In particular, many women, elderly people, black people, disabled people, gay men and lesbians, and people labelled "mentally ill" or "mentally handicapped" suffer discrimination throughout the health service. This often leads to many people receiving a lower standard of care that they are entitled to.

Discrimination and prejudice in acute care

The most stark, and perhaps most widespread, form of discrimination in acute care in London is racism, with many black people experiencing some form of discrimination when they use hospital services. Instances of the different ways in which racism is expressed have been well documented in a number of reports and CHC visits, a few

examples of which will be given below.

A workshop held in Hackney on "Racism in the health service" illustrated several specific forms of racial prejudice:

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.

(Cornwell and Gordon, 1984, p.14)

The failure of health services to provide multilingual staff leads to misunderstanding, misdiagnosis and stereotyped assumptions that people who can't speak English are either mentally ill or stupid.

One community worker described how she had come across a man in accident and emergency who was about to be admitted onto a psychiatric ward. His first language was not English and staff had been unable to understand his problems. If the worker had not intervened and interpreted for him, his physical problems would have been classified as psychiatric. (GLACHC, black people and acute services symposium, 1991)

The following account of a nurse illustrates another dimension of discrimination, where NHS staff make racist assumptions about the culture and behaviour of black and minority ethnic patients:

When she [the nurse] was in hospital having a child, an Asian woman in the next bed was having a prolonged and obviously very painful labour. Understanding professional etiquette the nurse/patient did not intervene, but after a time she felt she had to intervene. When she suggested to the ward sister that the doctor should be called she was informed that it was not neccessary, because "these people" have a low pain threshold and cry out disproportionately.

(Kushnick, 1988, p.463)

In addition, conditions such as sickle cell disorders, which are predominantly found in black and minority ethnic communities, are given a low priority and the needs of sicklers are often not taken seriously.

At its worse, racism in hospitals can be in the form of open abuse, as described in a CHC visit report:

The lift bringing patients, parents, visitors and equipment to the ward is covered with the most appalling racist graffiti.

(Barnet CHC, 1990a)

These selected examples show the way in which black people are discriminated against on the grounds of race. False assumptions are made about other cultures, little attempt is made to understand people who can't speak English, and discrimination is institutionalised in the custom and practice of everyday hospital life. This leads to a situation where black people can feel they are second-class citizens.

The GLACHC symposium on "black people and the acute

services" (see Appendix 1) further highlighted some of these issues which appear to be endemic in London's NHS. It concluded that the impact of racism in acute care leads to black people being reluctant to even go into hospital:

The point of entry to acute services is often frightening and hostile to black people. Racist implications in service delivery are not always clear, therefore it is not easy to complain. There is an element of fear — you are putting your life into the hands of people who do not like or understand you.

The widespread incidence of racism is an intolerable situation and must be tackled at all levels throughout the health service.

Despite the vast majority of NHS staff being female, women can still find their views marginalised, and their feelings and wishes ignored. This is largely a result of the fact that the bulk of senior medical staff are men and often hold old-fashioned and sexist views about women.

Women commonly complain of being patronised by doctors who wrongly assume that their female patients are too feeble minded or emotional to make sensible choices or be involved in decisions about their care.

(AIMS, letter to GLACHC, May 1991)

Situations where a woman's wishes are not taken seriously are often compounded if she is black or from a minority ethnic group, as illustrated by the following report:

The Brent group found that Asian women who desired the presence of female relatives at the birth of their children and their participation in the rearing of the children, came up against disapproval from professionals who presumed that such desires were unhealthy because they differed from current theories about the role of husbands and about mother—child bonding.

(Kushnick, 1988, p.463)

This lack of sensitivity to women's needs is also expressed in other ways. For example, many women prefer to see a woman doctor, yet are often not given the choice (Women's National Commission, 1984). Women are also placed on mixed-sex wards without being given a choice of a women-only ward. This can be particularly difficult if women end up being in a very small minority amongst inpatients.

The experience of discrimination is not confined to black people and women, as a number of other groups of people also find their opinions and needs ignored when they go to hospital. The problems faced by disabled people are well illustrated by a comment from the Spinal Injuries Association:

Many paraplegics and tetraplegics do still occasionally make use of local hospital services. Although there are notable exceptions, a common experience is of limited physical access and patronising attitudes by professionals. There is frequently little or no understanding of the needs of disabled people and of the distinction between illness and disability.

(Spinal Injuries Association, letter to GLACHC, May 1991)

Gay men and lesbians also suffer from prejudice and stereotyping, with often oppressive assumptions being made about their behaviour and lifestyle. A conference on gay men and lesbians' experience of health care concluded that if they were visibly out as gay, they would often experience worse care from staff.

The problems experienced by lesbians who go into hospital, particularly if they are involved in a long-term relationship, are frequently acute. For many lesbians, it seems that the prospect of major surgery pales into insignificance compared with the difficulties of managing a same-sex relationship in a way least likely to upset the hospital.

(Oxford City Council, 1989)

Problems such as this may result in a lower-take up of services and much greater additional stress in addition to being ill.

Other groups of people, whose basic rights to fair and equal treatment are often denied through discrimiation, prejudice and misleading stereotyped assumptions, include people labelled as "mentally ill" and "mentally handicapped", elderly people, and people who are homeless. Parts 2 and 3 contain clear evidence of the ways in which the rights of elderly people and homeless people are denied.

Each of the above examples illustrates a general point. A wide range of different people, who make heavy use of health services, suffer numerous forms of discrimination when going into hospital. Highest priority must therefore be given to tackling discrimination in all its forms, and both protecting, and enhancing, the rights of all patients.

One of the most effective ways in which this could be achieved would be to make the composition of NHS staff much more representative of London's local communities. In particular, the recruitment of a much greater number of black people, women, and disabled people into senior staff positions, where they are currently very underrepresented, would be a major step forwards.

In addition to implementing a comprehensive equal opportunities programme for NHS staff, a number of other major policies would be an essential part of the fight against discrimination. These are discussed later in the section on equality and acute care.

Ensuring patients' rights

During the last decade there has been a growing demand for a clear set of patients' rights, established in law and implemented as health service policy. In the mid-1980s the Association of Community Health Councils (ACHCEW) published a Patients' Charter, setting out basic rights which should be ensured within the NHS (ACHCEW, undated). More recently, a number of other user organisations have published charters covering specific groups of users and particular services. For example, Cancerlink has issued a "Declaration of rights of people with cancer" (Cancerlink, 1990).

The Government's recent commitment to improving the quality of public services, set out in the Citizens' *Charter*, promises to be a good starting point for enhancing users' rights in the NHS. However, it is vital that the broad national standards set out in the Charter are

extended to include specific commitments to improving access to the full range of NHS services and to tackle discrimination in health care.

In addition, any national framework of patients' rights will have to be successfully enforced at a local level. This will require careful independent monitoring, an effective complaints procedure and good user advocacy services. Community Health Councils could be given greater powers and more resources to help carry out this important role.

Recovery after treatment and leaving hospital

Once a patient has been treated it is important that he or she is helped to recover, and is given good follow-up care at home or in the community. This is critical to long-term recovery and, if successful, will prevent relapse and readmission.

Convalescence

Services offering convalescence after hospital are poorly provided in London. This is of particular concern given the importance of this service for people who are homeless or living alone. A study of convalescence in West Lambeth Health Authority highlighted the need for improved services and supported the idea of community-based hospitals providing convalescent services (Fallows, 1989).

The Lambeth Community Care Centre is a good model for the development of continuing care services. It is a small community-based GP hospital offering assessment, continuing care and rehabilitation at a level intermediate between home and hospital (Winn and King, 1987). It thus ensures good co-ordination with primary care and social services. Its example should be copied elsewhere in London.

Leaving hospital

In 1989 the Department of Health (DoH) issued a circular on the discharge of patients from hospital, emphasising the need for proper arrangements to be made prior to a patient going home. This initiative aimed to tackle the widespread problems caused by early or inappropriate discharge. The circular recommended that all procedures for discharge should be updated following widespread consultation, and that routine monitoring needed to be introduced.

In particular, the DoH reiterated key points made by a Parliamentary Select Committee which emphasised the need to:

- provide families with the necessary information and reassurance about the care of the patient after discharge;
- · check on day of discharge that the patient was fit to leave hospital;
- inform the patient's general practitioner/community nursing service/social services of the patient's potential needs in time for them to be met;
- secure therapy assessment prior to discharge to ensure facilities in the home were appropriate to the needs of the patient concerned.

(DoH, 1989a)

As a consequence a number of London health authorities have tightened up their policies, and a few have introduced schemes to improve the organisation and liaison about discharge. However, a recent survey by ACHCEW (1990) found that in over three-quarters of those districts responding there was no written procedure.

Despite these attempts to improve the quality of discharge arrangements, leaving hospital still appears to be a major problem for many Londoners. In the GLACHC symposium on discharge (see Appendix 1) it was clear that many organisations representing users still believe that people are being discharged inappropriately because of the pressure on beds. This is confirmed by the fact that CHCs frequently receive complaints about discharge from hospital, either that it was badly organised or occurred too early.

Inappropriate discharge has major implications for a number of groups, with elderly, mentally distressed and homeless people particularly vulnerable if their social needs and circumstances are not taken into account. For some disabled or chronically ill people, a well-organised discharge is particularly important, as they may be admitted to hospital on a regular basis or have a series of acute admissions.

Discharge: the need for assessment and co-ordination

There have been a number of recent studies of discharge from hospitals in London (Lewisham and North Southwark CHC, 1988; Haringey CHC, 1989; Enfield CHC, 1990; Croydon CHC, 1991). A common finding has been the lack of a careful assessment of patients' domestic situation, with people being asked about their medical concerns rather than their social ones. Of particular concern is the fact that many patients are not asked if they have anyone at home to look after them. As a consequence, in Enfield, a number of elderly people were discharged from the accident and emergency department to an empty home. Some of the people interviewed in Lewisham said they had not been asked if they needed help as they did have someone at home, even though that person was not likely to be able to cope adequately. In addition, there was evidence presented at the GLACHC symposium on discharge that black people are likely to be subject to false assumptions about their extended family networks, leading to a lack of ongoing support from statutory services.

These situations could be easily avoided if people were asked about their circumstances and involved in decisions about discharge. Although this is an obvious and important procedure, it appears that it is often not carried out. In the Haringey study it was found that less than half of the people interviewed had been given the opportunity to discuss their discharge with a doctor, nurse or social worker before they left hospital. This often appears to be the result of staff shortages.

It is also essential to ensure good co-ordination with other agencies and GPs, in order that when a person needs support from community and social care services, this is organised. In Haringey it was found that nearly as many people were being discharged at the weekend as during the week. This is a problem, as community services

often cannot be organised at the weekend. In many hospitals it appears that there is no one person who takes responsibility for ensuring a patient's aftercare.

To improve this situation, there is a strong case for an independent service that is capable of taking a wider view of patients' social needs, and ensures co-ordination between agencies, when someone enters and leaves hospital. This has traditionally been the role of the hospital social worker. However, concern was expressed at the seminar on discharge, that hospital social work services are being cut back in many areas and hospitals are increasingly employing their own discharge officers to act primarily as bed clearers.

Information to patients

Greater importance needs to be given to providing information to patients, families and carers. A common complaint is that people do not feel they have been given enough information about either their follow-up treatment or the help available to them in the community. This can lead to serious problems as people try to cope at home on their own, or have difficulties with their recovery. A stark example of the problems which can be caused by giving inadequate information to people leaving hospital was recently reported in Hackney:

A ninety-two-year-old lady was admitted on the 13th January ... with heart failure. From her recollection subsequently, I would guess she was quite confused on the ward — she is normally perfectly lucid. ... Her discharge on the 28th was precipitate — only her friend who was there at the time was informed. It would appear that she was found to be diabetic while on the ward. No-one, not the patient, her friend or either of her nieces was informed about this but she was discharged on glibenclamide. No instructions were give about her medication. On 1st February my partner ... was called to her home. The patient was in a hypoglycaemic coma. Fortunately she responded to glucagon.

(Letter to Hackney CHC from a local GP, February 1991)

Improvements are being made in this area with some hospitals using information collected on admission to compile an information pack for when the patient leaves hospital. Such information booklets have been shown to be useful to both patients and medical staff (Sandler *et al.*, 1989).

Transport

The actual process of leaving hospital can be another problem area. For example, the Croydon study found that a significant number of patients had not been given sufficient notice before having to leave hospital, making it difficult for them to organise support at home. In Enfield there were several cases where elderly people were discharged from the accident and emergency department late at night, causing great problems for patients to get transport home.

As has already been discussed above, the non-emergency ambulance service is increasingly prone to delay which forces disabled people

to have to wait, sometimes for many hours, before they can be taken home. Other people, who are able-bodied, no longer qualify for ambulance transport, even though they may be in great discomfort and incapable of using public transport. A distressing example of the difficulties this can cause is illustrated by the problems one woman had trying to take a chronically ill child back from a stay in a London hospital in a district adjacent to her local health authority:

Our biggest problem was the day she was due to be discharged. "How do we get her home?" we asked. The ward staff were vague. The transport officer said we did not qualify for an ambulance and should contact our local health authority. The health authority referred us to our GP, but we were not an emergency, were safely in hospital and out of his area. My health visitor tried to get a volunteer driver, but failed since we were out of the district.

(NAWCH Update, 1990)

The need for good community and social care services

However good discharge arrangements might be in principle, it is vital that adequate follow-up services are provided to patients. With the cuts in many community health and social care services, this is becoming increasingly problematic.

A study in Ealing (Sundararajan, 1989) found that of 144 readmitted patients whom clinicians had identified as needing a follow-up visit from a health professional, only forty-five had definitely received such a visit. An example illustating this problem was given in the symposium on discharge, where a good case conference had set out an excellent plan for following up someone living in Newham who had a stroke. Despite these good intentions the aftercare services were not delivered. Similarly, the National Association for the Welfare of Children in Hospital also mentioned a situation where the community paedriatic nursing service was inadequate to enable a child to leave hospital after day surgery.

A number of CHCs have expressed alarm at what appears to be a deteriorating situation:

Great concern was expressed about the effect that the reduction in the social services in Harrow would have, particularly on the elderly and infirm being returned into the community.

(Harrow CHC, 1990)

Without adequate community support, much of the good work carried out in hospital will be wasted. This will lead to increased readmissions, the need for longer inpatient stays and generally greater pressure on the acute sector. The state of community health and social services can thus have a major impact on the hospital sector and must be taken into account when considering the future of acute services.

CHAPTER



Are acute services relevant to the needs of Londoners?

high quality acute sector should ensure that treatment and care are effective in dealing with all health problems, and that a comprehensive range of services, capable of meeting the needs of every Londoner, is available. Measuring the effectiveness of acute services, and assessing a population's need for them, are the central issues involved in the planning and development of services. The techniques used in this process will ultimately mould the future shape of acute care.

Since the inception of the NHS, issues surrounding the measurement of effectiveness and need have been seen as largely technical questions left mainly in the hands of the medical profession. In the last decade, however, this has been challenged as both managers and users have started to pay closer attention to the practice of medicine and the issue of need. The main motivation behind the increased managerial interest in these questions has been a growing concern about the escalating costs of health care. In contrast, the patients' and users' movement has wanted to make sure people are treated appropriately and have access to services which meet their needs.

These issues, the appropriate and effective treatment of people, and Londoners' needs for acute health services, will be discussed in the separate sections that follow.

The effectiveness of acute services

In order to evaluate the effectiveness of any service we need to clearly define exactly what it is trying to achieve. In very broad terms, the aims of acute medical services can be summarised as follows:

- alleviating pain and suffering;
- preventing illness from causing death or disability;
- helping recovery;
- preventing the recurrence of a particular complaint.

Once broad aims have been defined, then more detailed measurements can be used to see if the aims are being achieved. In this process the emphasis is placed on trying to measure 'outcomes' rather than 'inputs'; for example measuring the percentage of people recovering after using a particular service, or how often the complaint recurs, rather than measuring the number of beds or doctors available.

Indicators of outcome for some of these aims, such as the death rate or the number of people recovering after surgery, are reasonably

around research and the use of new technology, has had a powerful influence on the development of the capital's health services. It is therefore important to look at both the effectiveness, and the consequences for service priorities, of new technologies.

Consumers For Ethics in Research (CERES) believes that medical research should be subject to audit, and attention should be paid to "the future burden on public resources which are consequential upon, but not offset by, innovation" (Letter to GLACHC, April, 1991).

In order to evaluate the effectiveness of new technologies and examine the impact they may have on service delivery, all new procedures should be carefully evaluated before being routinely introduced. The best way of making sure this is done in a systematic way would be to set up a national programme of technology assessment in health care, in which national organisations representing users were involved.

Medical audit

At present there is no national framework for monitoring an individual doctor's clinical standards, although the recent introduction of medical audit is a first step down this road. Medical audit is basically a process of confidential peer review, where colleagues discuss and evaluate each other's practice. The aim is to identify substandard treatment and highlight examples of good practice.

So far there have been few attempts to involve users in the audit process, although a project in Lewisham has been set up to try to integrate patients' perceptions into the review of clinical standards (Richardson *et al.*, 1990). However, the DoH has recognised the importance of the user perspective in audit by suggesting that District Medical Audit Committees "will need to devise ways of ensuring that the patient's perspective is incorporated into the audit programme" (DoH, 1990b, p.8). This important policy needs to be fully implemented.

The effectiveness of care and support

Establishing outcome measurements for the effectiveness of non-medical aspects of acute services involving care and support is much more difficult. Some attempts are being made to set standards for nursing care and to develop nursing audit (Kitson, 1989), although this is still at an early stage.

One example which illustrates both the potential value, and the complex problems involved in the use of outcome indicators is the study of readmission rates. There are obviously a number of factors which determine whether a patient is readmitted, including unavoidable complications or relapse, premature discharge and inadequate domicilary aftercare. As a consequence the development of the readmission rate as a potential measure of outcome has been criticised (Milne and Clarke, 1990).

Despite valid criticisms of its inappropriate use as a crude measurement of outcome, the study of readmission rates is important. At a time when length of stay in hospital is continuing to decrease it is important to be confident that this is not having adverse effects on

patient care. In a study carried out in Leicester (Jones, 1986) it was shown that the readmission rate had increased by thirty-eight per cent for medical specialties between 1977–83. The main reason given for this was the shorter length of stay, which decreased by over fifteen per cent in the same period.

A number of CHCs in London have anecdotal evidence to suggest there have been significant increases in the number of people being readmitted to hospital after treatment in recent years. In a survey of local GPs carried out by Haringey CHC (1991) forty per cent of respondents believed that some of their patients had been discharged from hospital too soon.

The evidence of increasing readmission rates illustrates a critically important point. Without careful evaluation of service outcomes it is impossible to assess the impact which the ever-shorter lengths of stay in hospital are having on patients' long-term recovery. Shorter stays may actually help recovery as people feel more comfortable at home, or alternatively they may lead to premature discharge, much suffering and increasing readmissions. In the worst case there may also be quite heavy additional costs involved in an increasing readmission rate, which could well offset any potential financial savings from increased throughput. The truth appears to be that no-one really knows at present.

Londoners' needs for health services

How are needs assessed?

Defining the "need" for health services is a complex and often philosophical question, open to a number of varying interpretations (Ware and Goodin, 1990). Since the 1970s attempts to assess needs and plan the development of services have depended on population-based measurements, such as the incidence of mortality, morbidity or the prevalence of a particular disease. This process was seen as a largely technical exercise which involved gathering and interpreting information, and then deploying resources on the basis of national and regional norms, targets and priorities. These were presented at a district level in the form of rolling strategic plans and annual operation plans.

With the introduction of the 1990 NHS and Community Care Act important aspects of the planning system have changed. Health authorities are now being given the task of purchasing care on behalf of the local population, through a series of service contracts with a range of provider units, including directly managed hospitals, self-governing NHS Trusts and private hospitals. As a consequence, greater priority is now being attached to the process of "needs assessment". However, the process of assessing needs remains largely unchanged and technical in nature, whereas the planning and implementation of policy has been radically altered towards a market model.

In auditing the quality of acute services in London we are concerned with the relevance of exisiting provision to the needs of Londoners. This involves focusing on two questions:

• Do users feel the right services are being provided?

• Are there areas of unmet need in the provision of acute services in London?

Inevitably conclusions about these questions will involve a judgement about the strengths and weaknesses of the system of priorities, planning and management which existed before the recent changes. They should highlight potential advantages and problems inherent in the new system. These questions will be discussed in the conclusion.

Do users feel the right services are being provided?

In general there is widespread support for most existing acute services and broad agreement between doctors and users about the best way of improving care. However, there are a number of areas where groups representing users feel that services could be improved. In some cases there appears to be support for the further specialisation of medical services for people who are heavily dependent on particular technologies or intensive care. In contrast, a number of services are thought to be too highly medicalised and could instead be developed as primary care services in a community setting.

These two seemingly contradictory views have been picked out as they highlight a central policy question. What is the appropriate level of medical and technological intervention in a particular health problem and how should services be organised to reflect this?

Too much medicine?

The central belief of medical science is that the causes of disease and ill health can be understood in largely biological terms. The "medical model" sees the body as a complex mechanism where illness is caused by disorders in the biological machinery. Generally the validity of this model is unquestioned and has resulted in many important advances in the understanding of health and disease.

In the last twenty-five years, however, there has been a growing challenge to the orthodox medical explanation of a number of important health problems. In particular, many users now feel that the problems faced by people going through a severe emotional crisis or suffering acute mental distress do not fit so easily into the medical model. Psychiatry has traditionally seen mental health problems as largely biological or "organic" in nature, caused by a disorder or disease of the nervous system. However many other professionals and above all users themselves now see many mental health problems, such as depression, in largely social and emotional terms (see Part 2: "Acute care for older people").

These different approaches to the understanding of mental health problems have important consequences for the type of care offered to people in distress. The dominant medical model has meant that, until recently, the only services available to people in acute mental distress were organised in acute psychiatric wards, based on extensive use of the major tranquillisers, and involved compulsory segregation from the community and everyday life. In contrast, many groups representing users of mental health services see hospital-based services as oppressive

and would instead like to see services based in the community with the minimal use of mood-altering drugs.

For example, the National Association for Mental Health (MIND) believes that:

...acute hospitals can be unsuitable for people in distress and wish to see an expansion of non-hospital crisis facilities.

(Letter to GLACHC, April 1991)

In particular people should be given the choice of being supported in their own home, or having asylum in a crisis house or in a small hospital unit. The emphasis here is on practical support, human contact and counselling.

A number of London health authorities currently have crisis intervention services in operation, including Napsbury Hospital (Barnet), Tower Hamlets and Lewisham. Here support and counselling is offered to the distressed person in his or her own home by a team of health workers. Another example of a user-based service is the setting up of a "crisis house" in Camden run by people with experience of using mental health services. In both these cases the focus has been switched from control and confinement to support and asylum.

A similar discussion about the appropriateness of services exists in maternity care where aspects of the medical management of childbirth are being questioned by many user groups. There is now a widely-held view that maternity services are becoming too medical and technical in focus, with an increasing emphasis on childbearing as a risky and pathological condition, rather than a natural process. One consequence of this "medicalisation" of childbirth has been the continued integration of maternity services into the hospital system and the increasing use of interventionist obstetric techniques in labour. As mentioned in the previous section the routine use of a number of these procedures is now a question of open debate between user groups and medical staff.

The Association for Improvements in the Maternity Services has argued for increasing women's choice about where and how they can have their baby:

Women should be given better information and much greater choice about how they can have their baby and the different maternity services available to them. Each health authority should aim to provide a women-centred service where the needs of the user come first.

(AIMS, letter to GLACHC, May 1991)

Despite these important criticisms, nearly all user groups recognise that medical services have an important role in the total package of services. For example, it is widely accepted that some mental health problems are undoubtedly caused by diseases of the nervous system, and some women's pregnancies will be difficult, requiring careful monitoring and obstetric intervention. In both these cases the involvement of hospital services is essential, but the contentious issue is about striking the correct balance between primary and social care services, and acute

medical care. In both maternity care and mental health there is a powerful argument in favour of changing the focus of services by developing them at the community and primary care level.

More specialist medical care?

In contrast to the issues of inappropriate care described above, there are important developments in both medical practice and the organisation of hospital services which have been broadly welcomed by groups representing users. This is especially true of the trend towards services dedicated to a particular user group or disease. The main advantages of such specialised services are the use of highly trained staff, the easier availability of new techniques and equipment, and more intensive nursing care. For example, the Chest, Heart and Stroke Association believes that:

rehabilitation is best effected in a specialised stroke unit which groups stroke patients together. In that way all members of the rehabilitation team are aware of the contribution of the others and failures in communication may be avoided.

(Letter to GLACHC, April 1991)

Similarly, the UK Thalassaemia Society support the creation of a "Supertransfusion Centre" devoted to the thalassaemias and related disorders:

where patients can walk in for treatment confident that their needs will be met by specially-trained doctors and nurses, and where drugs and equipment for their treatment would be readily available.

(Letter to GLACHC, April 1991)

This would have the considerable advantages of a greater continuity of care, and treatment by staff who are familiar with thalassaemia.

Although these two examples illustrate the potential benefits which specialist services offer, their development in other areas is more problematic. In Part 2: "Acute care for older people", it is pointed out that although some patients fare better receiving care from specialist geriatricians, there are major debates about how such people are to be selected, with London health authorities operating a number of different policies. It is also clear from Part 3 "Acute care for single homeless people", that the development of a few specialist services for homeless people has had little or no impact on the way they are treated in most acute hospitals.

Developing appropriate acute services for London

The two themes discussed above demonstrate that there is no simple model for, or consensus about, the future organisation of acute services. Instead it would appear that groups representing users sometimes identify quite different ways of improving care from medical staff, depending on the type of service currently available and the main user group concerned. As a consequence there is a powerful case for widening the process of needs assessment and service planning to include the views of the public and organisations which represent

particular groups of users. There are a number of possible ways in which this could be done:

- surveying public opinion about existing provision and areas in need of improvement;
- establishing outreach and community development projects to help identify the needs of particular groups;
- directly involving user groups in the process of needs assessment and the planning and evaluation of services.

Already attempts have been made to involve user groups in the debate about needs, as demonstrated by a recent consultation exercise by Merton and Sutton CHC (1991b), in which a wide range of voluntary organisations were asked for their views on local health services.

This type of initiative could become an important part of the recent requirement for each health authority's Director of Public Health to produce an annual report. Such reports should be produced independently and only after close collaboration with the CHC, local voluntary organisations, user groups, the FHSA and the local authority.

Although it has not been possible to carry out an in-depth audit of London's acute services, a number of important areas of currently unmet needs have been identified earlier and are summarised in the conclusion to this working paper. It is important now to examine the last, and possibly most significant, of Maxwell's criteria for a high quality service: equity.

Equality and London's acute services

The founding of the NHS enshrined a commitment to everyone's right to equal access and treatment in health care. Whilst a health service funded out of general taxation has largely ensured that everyone has equal economic access to health care, it is clear from the discussion in previous sections that there are other important barriers to turning the promise of equal treatment for all into a reality.

Inequality in acute health care manifests itself in the following three closely interrelated ways:

1 Direct discrimination against a number of groups of people

There is clear evidence of widespread racism, sexism and discrimination on the grounds of a person's age, sexuality, physical or mental ability throughout the NHS. This can take many forms, including insensitivity, prejudice, open hostility and the use of stereotyped views and global assumptions about culture and behaviour. As a consequence many black people, women, lesbians and gay men, older, disabled, chronically sick and homeless people receive a lower standard of care. This is often compounded by a lack of respect for their rights.

2 Institutional barriers to equality

Discrimination and unequal treatment is also expressed and reinforced in the organisation, policies and priorities of acute services. A number of important examples have been described above, including:

- lack of multilingual staff, interpreters or services for people whose first language is not English;
- little written information in languages other than English or in a form accessible to people with sensory impairments;
- limited physical access to hospital buildings.

Each of these shortcomings means that black people and disabled people do not have the same access to acute care as someone who is white or able-bodied.

At present relatively inadequate and poor quality services are still being provided for so-called "priority groups", including disabled, chronically ill and elderly people. As a consequence many users do not have easy access, or equal entitlement, to health services which meet their needs.

In addition, the underfunding of a number of services, including non-emergency transport and elective surgery, has resulted in increasing numbers of users having to pay for basic services which were previously free. This inevitably means that people on lower incomes have less access to these services.

3 The burden of ill health and disability is distributed unequally between different groups in society

As mentioned in the introduction, there are major inequalities in health status between different social classes, with working class people being more ill, disabled and more likely to die prematurely than people from middle class and professional backgrounds. This particularly affects black and minority ethnic people, elderly people, chronically sick and disabled people, who in general have a low social and economic status.

Thus many of the groups who have the least access to services and receive the poorest quality of care also have the worst health and the greatest need for services.

It will require a strong commitment to realise the goal of equality for all, as this means tackling individual and institutional forms of discrimination, removing barriers which stand in the way of easy access to services, and significantly reducing inequalities in health. A number of broader social policies, which are beyond the scope of the NHS, are required to achieve these goals, although the acute sector could make a vital contribution by:

- improving access to health services. This would involve ensuring easy physical access to buildings, improving communication and information given to users, and providing good primary care;
- the implementation of a comprehensive equal opportunities policy to tackle all forms of discrimination. Importance should be attached to making sure the employment of staff at all levels better reflects the make-up of London's local communities. Staff should be trained to treat everyone as an individual and to tackle discrimination. User

advocacy schemes should be established to help improve the rights of disadvantaged groups;

- improving services for "priority groups". The long-standing commitment to improve services for elderly, disabled and chronically ill people must be put into practice;
- providing more health services in areas of greatest deprivation and lowest health status. Health authorities should seriously consider expanding services in areas of poorest health and greatest need as part of a strategy to redress inequalites in health. In setting priorities for the future development of acute services in London the objectives of tackling discrimination and redressing inequalities must be given the greatest importance.

A strategy to improve the quality of London's health services for users, and to restructure the way that acute care is planned and delivered, is outlined in Part 4: "Conclusion". In Parts 2 and 3 the experiences of elderly people and single homeless people are examined. These highlight a number of issues relevant to the whole population of London, but which are particularly of concern to these groups.

well developed. However, attempting to establish a cause and effect relationship between the activity of acuter services and these outcome indicators is extremely difficult. For example, the process of long-term recovery from head injury is poorly understood and may depend on a number of factors including a patient's behaviour, their wealth and the support they receive from their family and friends. It is therefore problematic to evaluate the impact of, for example, rehabilitation services in the recovery process.

However, there are two components of acute services which lend themselves to meaningful evaluation: the effectiveness of clinical interventions, such as surgery or drug therapy, and the effectiveness of care and support, including nursing services and the length of hospitalisation.

Measuring clinical effectiveness

Medicine is often presented as a rigorous science, based on experiment and conclusive evidence. With the use of some routine procedures this may indeed be the case, but it is often surprising for lay people to find that there are major debates and disagreements over clinical practices within the medical world (Wennberg, 1986). For example, the use of Caesarean section in childbirth, the treatment of breast cancer, or the rate of tonsil operations varies considerably between clinicians (Francome, 1989 Gazet *et al.*, 1985; Bloor and Venters, 1978).

Furthermore, many procedures, especially surgical ones, still demand a high level of skill and judgement, with techniques often varying from one clinician to another. As a consequence, there is some evidence that some of the most fundamental indicators of clinical outcome, such as the rate of post-operative death can vary quite considerably between different doctors (Buck et al., 1987). The reasons for these variations are often complex and may be affected by a surgeon's workload, the case mix, the hospital environment (for example the prevalence of infection) and the organisation of services.

In reviewing the variation in clinical activity, Wennberg (1988) concludes:

Too often physicians simply do not know what works best to improve the health of the patient... The problem is that no-one knows which rate of utilisation (of a clinical procedure) is right. Outcome studies are thus needed to restore the prerogative of the medical model and make it possible for resource allocation to be based on need and expected outcome.

It would therefore appear that with many medical procedures there is still too little information available to enable firm conclusions to be made about either how often they should be used, or how effective they really are. As a consequence there is a powerful case for a more rigorous evaluation of routine procedures, the setting of national clinical standards, and closer monitoring of the practices of individual physicians.

However, it would be a mistake to measure the effectiveness of a procedure simply in clinical terms alone, as this ignores an important dimension – the feelings and opinions of users about the treatment. In

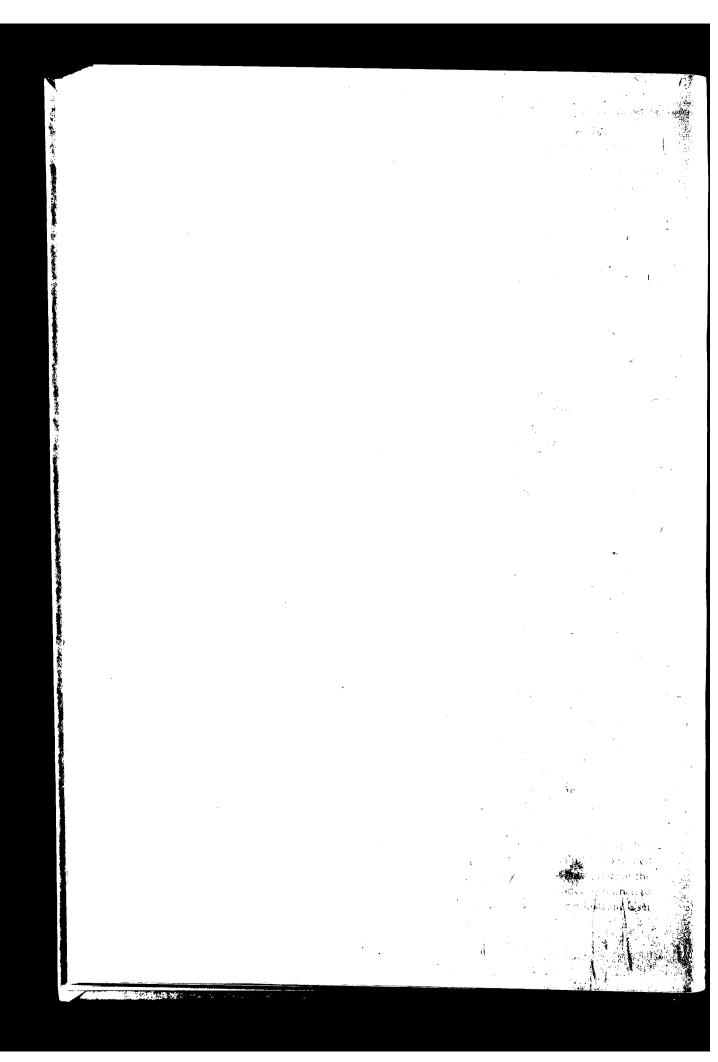
many areas, such as elective surgery, the effectiveness of a procedure appears to correspond closely with the satisfaction of patients; if a hip replacement operation is successful patients will generally be very happy with the outcome. With other techniques the situation is less clear cut. For example, with surgery for breast cancer there are a number of options available to the clinician, each of which involves different amounts of risk and pain and significantly different effects on a woman's long-term feelings of well-being after recovery. Given that there are major differences in opinion and practice between doctors about the treatment of breast cancer (Gazet et al., 1985), it would seem to give women more information and choice about treatment, and to set standards which would avoid the unnecessary use of radical breast surgery. This was the conclusion of the King's Fund Consensus conference on the management of breast cancer (1987b), which brought together users and clinicians to establish common ground. This type of exercise is a valuable way of setting standards and should be extended to cover other areas.

A good example of the diversity of clinical opinion is in child-birth, where the debate about the evaluation of routine clinical procedures has become particularly important to the users of maternity services. Over the last twenty-five years there has been a very significant increase in the rate of obstetric intervention in labour. In particular, the use of Caesarean section has more than trebled and nearly one baby in nine is now delivered surgically. Yet the reasons for this increase are not at all clear and have been seriously questioned by both user groups and some clinicians (Francome, 1989). In addition, a study by the Maternity Alliance has revealed very large differences in the rate of obstetric interventions, with the incidence of Caesarean section ranging from nil to twenty-five per cent between different maternity units (Boyd and Francome, 1986).

Given the risks involved in surgery, and the likelihood that no woman would choose to have her baby by Caesarian section unless absolutely necessary, there is a powerful case for careful evaluation and tighter control of this procedure. It is essential to fully involve users in this process, in order to ensure that all aspects of care are taken into account. National organisations representing users have a wealth of experience and expertise in their specialist areas and some have already carried out surveys of users' views and experience of medical procedures. The National Childbirth Trust (NCT) has conducted two extensive surveys on the rupture of membranes in labour, and the incidence of postnatal infection (NCT, 1988 and 1989). Despite some criticisms about the methodology of these surveys, they have highlighted important issues and demonstrated the value of user-based studies.

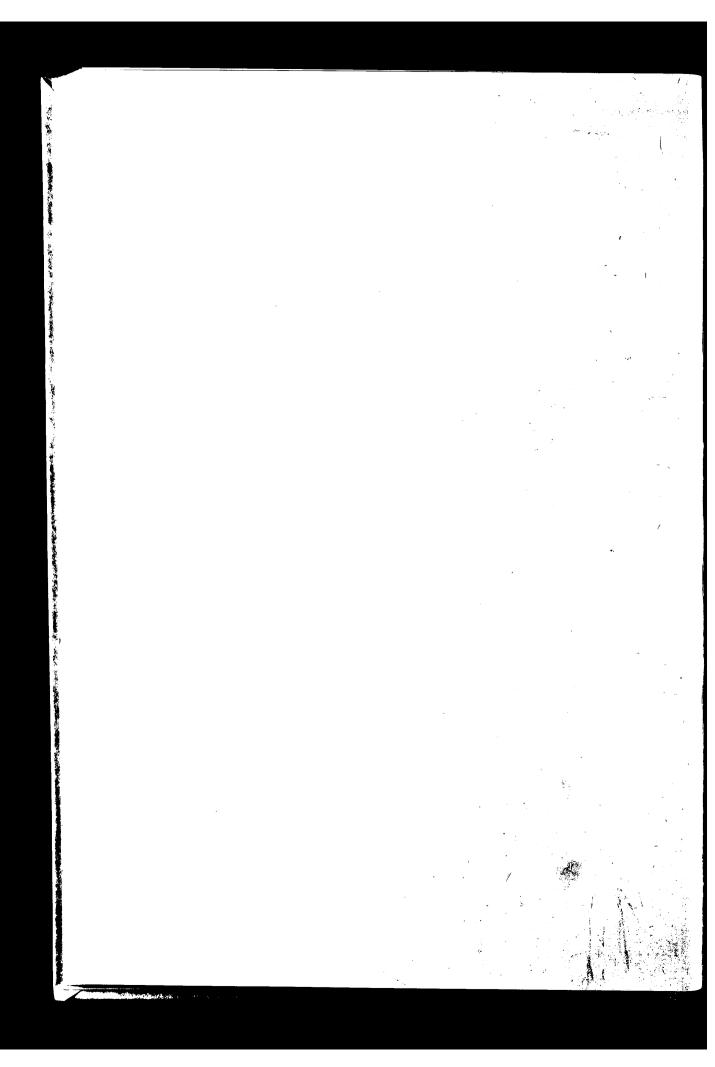
Evaluating medical research

Another important area related to establishing clinical standards is the evaluation of new medical procedures and research. In London the high concentration of special hospitals and medical schools, often based



Part 2

ACUTE CARE FOR OLDER PEOPLE



CHAPTER



Introduction: Elderly people and health

In selecting the acute care of older people as a focus of this section, the following factors were particularly influential:

- Firstly, elderly people are a very substantial group of health service users. Over sixty per cent of non-psychiatric hospital beds are occupied by people aged over sixty-five, and over forty per cent by people aged over seventy-five. A person aged between sixty-five and seventy-four is almost two-and-a-half times as likely to be admitted to hospital as someone aged between fifteen and forty-four; admission is around four times as likely for a person aged over seventy-five (DHSS and OPCS, 1987).
- Secondly, elderly people are more likely than younger age groups to be cared for in the major specialties, such as general surgery, general medicine, trauma and orthopaedic surgery, and geriatric medicine, which are provided in almost all health districts. Community Health Councils have long argued that in London these specialties take second place to the smaller but more prestigious specialties associated with London's many teaching hospitals (Davidson, 1980). This section gives an opportunity to examine the implications of this for a particular group of health service users.
- Thirdly, the study offers a chance to examine how well the NHS meets the needs of a socially disadvantaged group. The average income of elderly people is far lower than that of any other age group (Thompson, 1990), and discrimination on the grounds of age remains widespread (Falconer, 1991). This has been the subject of much debate: whilst the proponents of the creation of the NHS emphasised that its aim was to create equality in access to health care (Cmnd 6502, 1944), Navarro (1976) (amongst others) has argued that state-funded health care systems within a capitalist society tend to replicate and reinforce existing class relations.
- Fourthly, elderly people frequently have a complex and interlocking set of primary, acute and continuing health care needs. Attempts to meet one of these needs without considering the others may be counter-productive; it is therefore essential to provide elderly people with a complete package of care, rather than isolated items of service. One of the main strands of criticism of the government's NHS reforms is that they will create divisions between acute and non-acute services (Nursing Standard and R.C.N., 1989); a review of the care of elderly people gives an opportunity to consider how such divisions can be avoided.

• Finally, whilst receiving health care elderly people's needs are not simply for medical treatment, but for a variety of therapies designed to meet their social, psychological and physical needs. Within acute hospitals there is a tendency for the 'medical model' to dominate; this section will attempt to examine how far this affects the services received by elderly users.

Many studies of health care for elderly people are concerned exclusively with services intended specifically for old people: in this document, the preferred approach is to look at all acute services used by old people. The rationale for this is that old age is primarily a social experience: to make sense of the part that health care plays in this experience it is necessary to consider it as a totality. This study is concerned primarily with non-psychiatric services, but the relationship between psychiatric and non-psychiatric needs is a very close one, and attention is drawn to the need for effective liaison between the relevant services.

How old is an old person? In the health service, old age is now more narrowly defined than in the past, with norms for provision generally expressed in relation to population aged over seventy-five or even eighty-five, rather than sixty-five. In social and economic terms, however, old age is beginning earlier, with a steady fall over the last fifteen years in the economic activity rate for people aged over fifty-five (Townsend, 1989). The health care needs of younger retired people would certainly merit further research; however, constraints of time and resources and the lack of readily available material mean that this study is concerned almost entirely with the needs of age groups older than this.

The term 'geriatric' is used frequently throughout this working paper to refer to medical care specifically intended for elderly people – which is precisely what the term means. It has, unfortunately, acquired a number of derogatory connotations; this has led people as influential as the then Chief Medical Officer of the Department of Health (Acheson, 1986) to suggest that an alternative term should be sought. However, it is still widely used, and convenience and clarity dictate its use here. The real challenge in the care of older people is to achieve not a change in terminology, but a change in attitudes.

Much of this study is secondary research – the collation and analysis of previously published data, studies and reports. This has been supplemented by information gathered from three sources:

- 1 The symposia organised by GLACHC in March and April 1991 (see Appendix 1), in particular the symposium on health care of older people. Papers giving a detailed response to the discussion document prepared for this symposium were received from Haringey CHC and Age Concern Greater London. The other symposia referred to in this chapter were on discharge from hospital and on black people's experiences of acute services;
- 2 Responses to a series of questionnaires (hereafter referred to as 'the questionnaire') sent to CHCs, acute services general managers and health authority purchasing managers (see Annex);

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3 Discussions with various people involved in service provision to, or advocacy on behalf of, elderly people.

The structure adopted in this report is as follows:

- 1 An audit of existing services, using the criteria for quality set out by Maxwell (1984);
- 2 An analysis of demographic trends, trends in service provision and plans, and a review of the implications of administrative changes.

CHAPTER



Audit of services

Access to services

In London there has been a steady drop in the number of acute hospital beds of around a quarter in the past ten years (GLACHC, 1991a) arising from the implementation of the RAWP formula combined with a period of relatively slow growth in expenditure on the NHS. As this has coincided with a period of rapid growth of the elderly population it has, not surprisingly, made any sort of hospital admission harder to achieve. The following case, reported by Haringey CHC, is certainly not unusual:

Elderly person felt by social services to be in need of admission to hospital. Consultant said in need of Part III home. Dispute about level of mobility. Consultant said reduction in beds was not hindering work but it was apparent they were being stricter about admission to beds.

Recent health service indicators show that the overall hospitalisation rate for people aged over sixty-five and resident in the London health districts differs little from that for the country as a whole (see Figure 6.1).

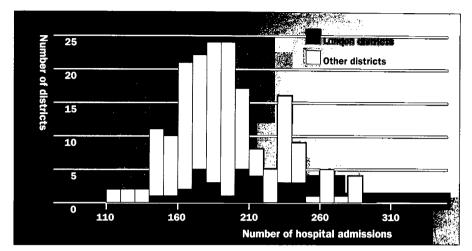
However, the emergency admission rate is substantially higher than the national average, whilst the elective admission rate is substantially lower (see Figures 6.2 and 6.3).

It has been suggested that the failure to provide appropriate elective care may be a significant cause of emergency admissions (Seymour and Pringle, 1983), but district by district the data for London do not suggest that there is a direct trade-off. Whilst the high emergency admission rate may be worrying in view of the generally less satisfactory outcomes of emergency admissions, it is clear that concern over access to services must centre on elective admissions. The problems here are reflected in low rates of certain generally lifeenhancing surgical procedures, for example hip replacement, knee replacement, and cataract surgery (see Figures 6.4, 6.5 and 6.6).

Whilst the variable quality of data makes health service indicators somewhat unreliable, the weight of evidence does suggest that elderly Londoners experience severe problems in obtaining access to elective acute hospital services. There is no readily identifiable single cause for this, but an explanation may be sought by positing the vicious circle shown in Figure 6.7.

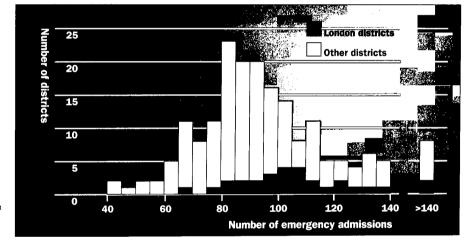
This presents the hypothesis that because GPs are aware of the low level of service for elderly people requiring elective surgery, they are less willing to perform their role of advising patients of the availability of appropriate treatment for their condition, or to make referrals to hospital; patient expectations become adjusted to the difficulty in obtaining

Figure 6.1 Hospital admissions per 1,000 district residents aged over 65



Source: 1988 Health Service Indicators, HR41

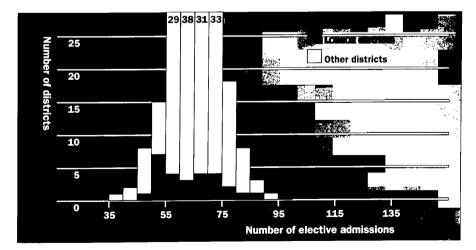
Figure 6.2 Emergency 1,000 district



admissions per residents aged over 65

Source: 1988 Health Service Indicators, HR42

Figure 6.3 Elective admissions per 1,000 district residents aged over 65



Source: 1988 Health Service Indicators, HR43

- care intended to enable people to return to their own homes. This can
 include treatment in hospital, respite care, and convalescent care;
- long-term residential care. This can be provided in hospital, nursing home, or residential home.

The following is a synopsis of the available information which indicates the level of provision in London in each of these three categories.

i. Care intended to help people remain in their own homes

Compared to the rest of the country, London is reasonably well provided with local authority day centres for elderly people (Chartered Institute of Public Finance and Accountancy, 1990), although at just sixteen places per thousand population aged over seventy-five this is relevant only to a very small number of people. Of those people aged between sixty-five and seventy-four in London, 2.9 per cent have a home help, as against 3.2 per cent in the rest of England, and 15.1 per cent of people aged over seventy-five in London have a home help, compared with 14.4 per cent outside. The metropolitan districts outside London, however, have a substantially higher level of provision: 4.8 per cent of the population aged between sixty-five and seventy-four receive a service, and 20.5 per cent of the population aged over seventy-five. Outer London has substantially lower provision than inner London in both local authority day centres and home helps.

A point which was raised in the symposium on health care for older people was that the increasing professionalisation of the home help service meant that home helps were now less willing to perform some basic tasks which had previously been seen as a part of their job. Age Concern Greater London in its submission raised a similar concern:

The growing trend towards intensive home care for a small number of elderly people "in greatest need" and the consequent diminution of home help services means that a sizeable proportion of vulnerable elderly people who are not "in greatest need" are neglected and placed at risk.

This highlights the danger that resources for care in the community will be found not through a reduction in the need for hospital services, but through a squeeze on resources for community preventive services.

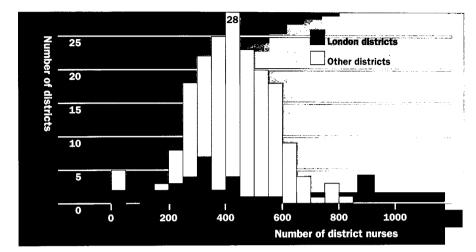
The level of district nursing provision in London is markedly lower than elsewhere in the country, as demonstrated by the health service indicator given in Figure 6.8.

Age Concern Greater London has undertaken detailed investigations into two services of particular importance for elderly people living in their own homes: chiropody services (Collyer and Hanson-Kahn, 1989) and bathing services (Collyer and Hanson-Kahn, 1990). In relation to the former they found a marked shortage in the number of chiropodists, with long waits for treatment, whilst their study of bathing services found that health authorities and local authorities were "passing the buck" between them. The shortage of chiropody services is borne out in a study undertaken by City and Hackney Health Authority (1990a), which found that the greatest unmet self-reported need in the community was for chiropody services.

In its submission Age Concern Greater London also drew

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Figure 6.8
District nurses per 100,000 district residents



Source: 1988 Health Service Indicators, DN23

Figure 6.9

Percentage of patients from inner London districts aged over 75 discharged from general wards, who had occupied a bed for over 28 days

Source: 1988 Health Service Indicators, LS63

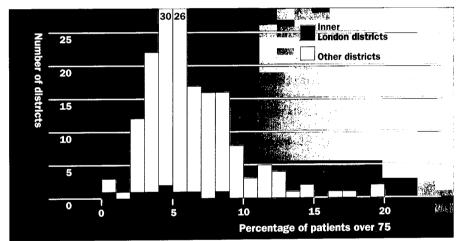


Figure 6.10

Percentage of patients from outer London districts aged over 75 discharged from general wards, who had occupied a bed for over 28 days

Source: 1988 Health Service Indicators, LS63

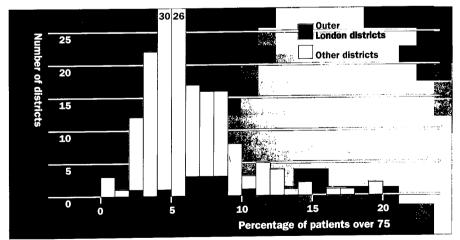
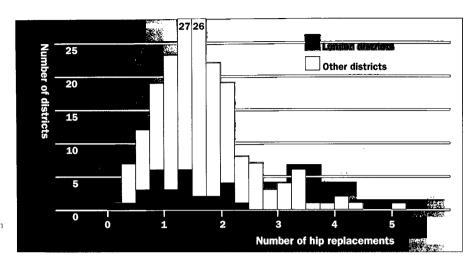


Figure 6.4

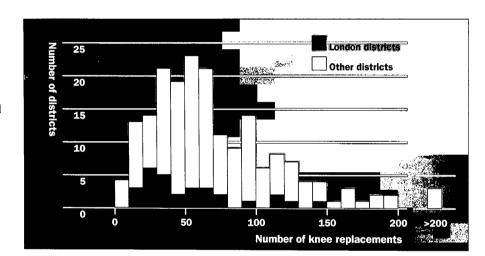
Hip replacements per 1,000 district residents aged over 75



Source: 1988 Health Service Indicators, HA54

Figure 6.5

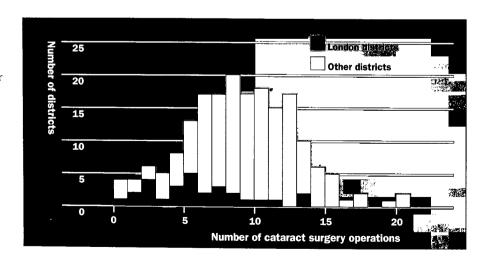
Knee replacements per 1,000 district residents aged over 65



Source: 1988 Health Service Indicators, HR48

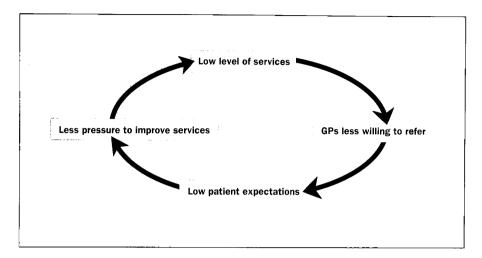
Figure 6.6

Cataract surgery operations per 1,000 district residents



Source: 1988 Health Service Indicators, HA55

Figure 6.7
Pressures
against
improving the
health service



referrals, and thus pressure to improve the level of service is lessened. It does not in itself explain how such a vicious circle might have come into existence, or the pressures that maintain it. However, drawing on previous work and information gained in the course of this study it is possible to identify pressures working on all points in the circle:

1 Low level of service

Whilst waiting list data must always be treated with caution (Yates, 1978), they are an important indicator of the adequacy of resources devoted to elective surgery. At the GLACHC symposium, a good deal of frustration was expressed at the length of waits for treatment. It was felt that in a lot of cases waiting lists had become a fiction, as people on them had very little chance of ever being treated. A comparison of the proportion of districts in London having long or short waiting lists for the four surgical specialties most used by elderly people, with the proportion of such districts in England as a whole, yields the following results (Rigge, 1990):

Table 6.1
Waiting lists in London districts for the four surgical specialties

Source: Adapted from College of Health guide to hospital waiting lists (Rigge, 1990)

	% of districts with short waiting list (less than 5% on list for over a year)	% of districts with long waiting list (30% or more on list for over a
	year)	year)
General Surge	ery	
London	3.4	44.8
England	12.1	29.5
Trauma and C	rthopaedics	
London	0.0	51.7
England	12.4	33.9
Ophthalmolog	ıy	
London	28.6	28.6
England	30.9	18.1
Urology		
London	8.7	34.8
England	18.9	32.0

The only satisfactory explanation for the absolute consistency of this data is that London health authorities are not devoting sufficient resources to elective surgery. The probable reason for this is to be found in the resource cuts London health authorities have experienced. Cutting the amount of planned elective surgical activity is one of the easiest ways to achieve substantial cuts in spending, and surveys of cuts in London health authorities have indeed shown that such activity has been disproportionately affected (Wiles, 1991).

2 GP reluctance to refer

Whilst the difficulty in obtaining a service promptly is likely to deter a GP from making referrals to it, inadequacies in the GP service itself may also act as a block on appropriate referrals. Concern with GP services in inner London has been long-running (Acheson (Chair), 1981); older GPs practicing in isolation from their colleagues (of whom there are more in London than elsewhere) may well find it particularly difficult to make appropriate referrals for the many elective surgical procedures which have developed in the last twenty years. Whilst elderly people undoubtedly constitute a substantial part of all GPs' workloads, at least one survey in London did find concern amongst other professionals that GPs did not give sufficient priority to meeting the needs of their elderly patients (Buckton and Wiles, 1989). Age Concern Greater London pointed out in its submission to GLACHC that:

the "What can you expect at your age?" attitude ... is one with which Age Concern is all too familiar. This attitude in turn reflects a lack of interest which many GPs still show in elderly people's health care needs.

Age Concern Greater London also drew attention to the problems of homeless elderly people in obtaining access to health care (see Part 3: "Acute care for single homeless people").

3 Low patient expectations

The extent of acclimatisation to a low level of service is clearly shown by the fact that CHCs receive very few complaints about waiting lists, despite the poor record of London health authorities — a point confirmed in their responses to the questionnaire dispatched in connection with this study. There are also social factors which may make London's population less effectively assertive in relation to health care: London contains a concentration of the most socially deprived health districts in the country (Department of the Environment, Inner Cities Directorate, 1983); people living in such circumstances are likely to have less access than the middle classes to information about the potential of treatments (Titmuss, 1968), and have greater difficulty in obtaining care (Tudor Hart, 1971).

4 Less pressure to improve services

In addition to low patient expectations, the concentration of private medicine within London serves as a means of reducing the pressure on the NHS to improve services, especially the routine surgical services in which the private sector specialises. Around half of all beds in private

acute hospitals in England are in the Thames regions. Despite London's relative socio-economic deprivation around twelve per cent of its population is covered by private health insurance – a higher proportion than anywhere else in the country outside the South East (OPCS, 1989). It was clear from the symposium on health care for older people that for quite a number of elderly people the private sector was seen as a way of overcoming disappointments with the NHS. An example was presented by a representative of an Asian elderly organisation:

One of our members was sent to an NHS hospital for cataract surgery, but he was told that the cataract was not "ripe". So he went to a private hospital and the operation was done immediately.

Despite the recently-introduced tax incentives for elderly people to take out private health insurance, private medicine will always remain the preserve of a small minority of elderly people. In London, there is a danger that this minority will become just large enough for routine NHS treatment to be seen as a second-class option. If this comes about, then the vast majority of elderly people will be losers.

Relevance of service to community need

An assessment of the relevance of acute hospital services for elderly people to the needs of the community must contain several elements: an assessment of the part that acute hospital services play in the total "package" of care, consideration of how demographic factors affect the need for different elements of the "package", and a review of the balance between the types of acute hospital service available.

1 The role of acute hospitals in the total "package" of care

Horrocks (1986) has identified the following as essential components of a comprehensive service for the elderly:

- provision of personal preventive care;
- limitation of social isolation;
- · provision of sheltered housing;
- provision of domestic support services;
- provision of domiciliary nursing care;
- support to carers;
- · access to geriatric services and rehabilitation;
- · provision of acute hospital services;
- provision of long-stay care.

In this document a greatly simplified approach will be adopted. Broadly speaking, care provided to old people can be divided into three categories:

care intended to help people to remain in their own homes. This can
be either institutional (day centres, day hospitals, etc.) or domiciliary
(district nurses, home helps, sheltered housing wardens, etc.);

attention to shortages of physiotherapists and occupational therapists. The shortage of community occupational therapists is particularly acute: the significance of this is demonstrated in another study reported by City and Hackney Health Authority (1990a), which demonstrated the dramatic number of elderly people with osteo-arthritis whose ability to cope at home would be significantly improved by the provision of fairly simple aids.

Another essential to maintain the health of elderly people living in their own homes is access to adequate finance. At the GLACHC symposium the view was expressed that most GPs had little knowledge of benefits, and attention was drawn to a computer package on benefits which had been piloted by Dr Brian Jarman at the Lisson Grove Health Centre.

ii. Care intended to enable people to return home

In this study no attempt has been made to compare the availability of respite and convalescent care in London with that elsewhere, but it may be noted that the demand for more convalescent care was one of the main themes of the discharge symposium. As has been shown above, the overall hospital admission rate for elderly people in London is about in line with the national average. However, the proportion of elderly people staying in non-psychiatric hospitals is slightly above average. There is a very marked difference in this between inner and outer London, with longer stays being less frequent than the national average in inner London, but much more frequent in outer London (see Figures 6.9 and 6.10).

Studies of reasons for elderly people staying a long time in hospital have suggested that the primary factors determining length of stay are diagnosis (Maguire, Taylor and Stoat, 1986) and organisation of hospital services (Coid and Crome, 1986). However, these studies have been based on data from single districts: an explanation for the systematic difference between inner and outer London might be found in the greater pressure for a fast throughput in teaching hospitals, or the lack of community and social support services in outer London, or a combination of both these factors.

iii. Long-term residential care

The overall proportion of elderly people in residential care within London, combining figures for local authority, voluntary and private homes, is rather less, at twenty-four per thousand population aged over sixty-five (London Research Centre, 1989), than for the country as a whole, with twenty-nine per thousand population aged over sixty-five (Department of Health, 1990). This does not necessarily mean that it is harder for elderly people from London to obtain residential care, but that moving into residential care is often accompanied by a move away from familiar territory, friends and relatives. This was identified at the GLACHC symposium as a major source of concern to elderly people.

2 The effect of demographic factors

The proportion of old people within the Greater London population does not differ significantly from that for the country as a whole.

However, two factors stand out: the high proportion of single elderly people (OPCS, 1984), and the relative mobility of the population (OPCS, 1983), making informal community support less likely. The implication of this for service-providers is that a substantially higher than average level of paid support will be necessary to maintain ill or disabled elderly people in the community. The fact that, as shown above, community support to elderly people living in the community is, at best, average, may well go some way to explaining the far higher than average level of emergency admissions of elderly people to acute hospital — which, in its turn, is an important factor in limiting the hospital resources available for planned surgical treatment.

3 The balance between types of acute hospital service

The imbalance in London between emergency and planned admissions has already been dealt with. Another aspect of acute hospital care is the balance between geriatric and non-geriatric care for elderly people. As can be seen in Figures 6.11 and 6.12 the picture differs markedly between inner and outer London.

Whilst the very low proportion of geriatric beds in inner London may well be attributable to the larger than average number of beds in other specialties in teaching hospitals, it was clear from the response to the questionnaire sent to acute service managers that one of the main factors determining whether an elderly person would receive specialist geriatric care was whether there was a specialist bed available. This does suggest that there is a good case for increasing the total number of geriatric beds.

Inner London also differs from outer London in relation to the proportion of elderly people amongst the recipients of acute hospital treatment as shown in Figures 6.13 and 6.14.

Whilst this may also be due to the special effect of teaching hospitals, it should be noted that the smaller proportion of elderly people receiving acute treatment in hospitals in inner London increases the risk that their special needs will be overlooked.

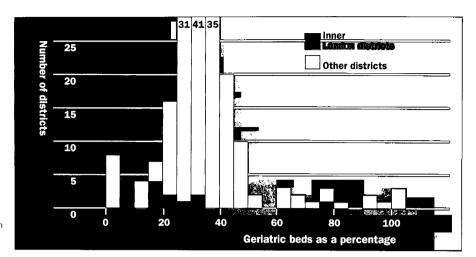
Effectiveness of services

The effectiveness of health services is measured by the extent to which their beneficial effects outweigh their harmful effects. In attempting to ascertain the effectiveness of acute services to elderly people in London, the various stages that an elderly person undergoes while experiencing an episode of acute care will be considered, from the moment that the need has been identified to the moment that the amount of care he or she receives is stabilised at a level they can expect to receive. These are:

- arrangements for admission, transport to hospital, and admission itself;
- treatment;
- nursing care and rehabilitation;
- · discharge and arrangements for post-discharge care.

Figure 6.11

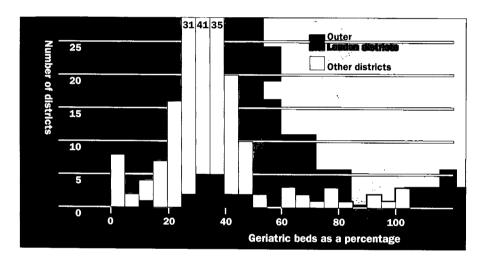
Geriatric beds in inner London districts as a percentage of beds on general wards



Source: 1988 Health Service Indicators, HB57

Figure 6.12

Geriatric beds in outer London districts as a percentage of beds on general wards

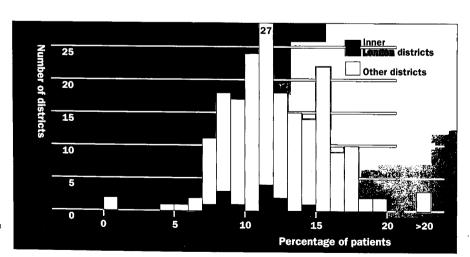


Source: 1988 Health Service Indicators, HB57

Figure 6.13

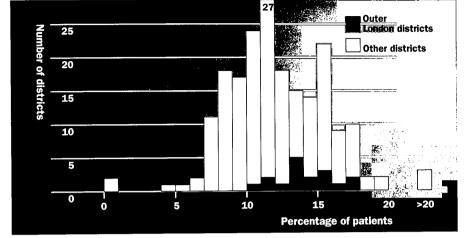
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Percentage of patients from inner London districts in acute specialties aged over 75



Source: 1988 Health Service Indicators, HA65

Figure 6.14
Percentage of patients from outer London districts in acute specialties aged over 75



Source: 1988 Health Service Indicators, HA65

1 Admission

One of the contributors to the GLACHC symposium identified the need for better preparation for hospital admission. The handling of admissions is by no means a new concern, having been the subject of a study as long ago as 1973 (Baderman *et al.*, 1973), but in recent years it has attracted only a fraction of the interest that has been directed to discharge.

An admission does represent a major upheaval, especially for an older person. There are several ways in which the health service in London is failing to minimise the anxiety that accompanies a planned admission:

- Firstly, pre-admission letters sent to prospective patients are frequently in language that is not easy to understand; individual details may be written in by hand. The availability of word processing and desk-top publishing means that personalised and, if appropriate, large-print letters could easily be sent.
- Secondly, around one in ten planned surgical admissions in the Thames regions is cancelled (Harman, 1991). One CHC had dealt with a case of an elderly man whose long-awaited orthopaedic admission had been cancelled when a telephone call to his sheltered housing warden (he did not have his own phone) had been unanswered.
- Thirdly, over the past year numerous London CHCs have reported a dramatic deterioration in non-emergency ambulance services (GLACHC, 1991). A survey of GPs undertaken by Haringey CHC (1991) found:

missed appointments at outpatients, physiotherapy and x-ray departments; increased levels of uncertainty and stress for patients and relatives; patients having to use taxis and minicabs where they had previously used the ambulance service, often when they could ill afford it; and increased workload for GPs in calming patients and making alternative transport arrangements. This resulted from ambulances being cancelled, being very late, not showing up when an order had been agreed; and ambulances being refused because patients were "outside the new regulations". Patients mostly affected seem to have been the elderly infirm and the partially disabled.

A social worker from the Middlesex Hospital who attended the symposium on health care for older people reported that her department had been asked to provide transport for a woman with glaucoma whose ambulance transport had been cancelled three times.

• Finally, people may not receive much of a welcome when they reach the hospital. Many London hospitals are large places, and they are likely to be reliant on the portering staff to get to the correct part of the hospital. As Haringey Community Health Council reports in its submission: "Both St Ann's Hospital and the North Middlesex have internal ambulances to take patients around the site. They are rather like milk floats and not very comfortable." In one case at St Thomas's Hospital in West Lambeth, elderly patients due to attend a newly-opened day hospital were left by portering staff in the outpatients department, as the porters were unaware of this facility and thought that the patients requesting to be taken to it must have been confused!

Unplanned admissions come either direct from the GP, or via the accident and emergency department. Dove, Dave and Gerard (1986) point out that in an accident and emergency department there is a constant temptation to assign people to admission or discharge without considering the need for, and possibility of, additional support in the community. They report that the attachment of an Age Concern officer to an accident and emergency department in Nottingham enabled a substantial increase in the number of patients discharged with support. At the Charing Cross hospital in London the use of a fairly simple social assessment form for people aged over seventy on the accident and emergency ward achieved a substantial improvement in the quality of discharges and much more efficient use of community services (Buck and Mills, 1988).

The questionnaire to acute service general managers elicited few examples of special facilities or procedures for elderly people in accident and emergency departments, beyond the possibility of referral to the geriatric team. In a couple of districts there were protocols governing the organisation of discharges, including such commonsense guidelines as not sending elderly people home late at night. Waltham Forest reported that elderly people waiting in the accident and emergency department were provided with sheepskin or Spenco mattresses to prevent the development of pressure sores. In Richmond, Twickenham and Roehampton a scheme of follow-up visits by a clinical nurse specialist to elderly people assessed in the accident and emergency department as being at risk has recently been started. A similar scheme using health advisers to follow up elderly attenders at the

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Homerton accident and emergency department is described in the City and Hackney Public Health Report (1990a); unfortunately, the effectiveness of these advisers appears to have been constrained by the shortage of community occupational therapy staff.

In many ways the ideal solution to the problems associated with hospital admission is to avoid hospital admission altogether. Although in some cases this is obviously not an option, a case has been made for the widespread development of "hospital at home" schemes (Clarke, 1984), in which the specialist health care resources usually confined to hospitals are made available to specific patients in their own homes. A recent report (Marks, 1991) re-examines such schemes. Responses to the questionnaire revealed that in about a third of London districts some form of intensive home support scheme was available, but in almost all cases such support was confined to people who had been discharged from hospital.

2 Treatment

Geriatrics has developed as a major medical speciality since the Second World War. Whilst it was originally concerned only with long-stay and chronically ill patients, there now appears to be a consensus that a substantial number of people will fare best if they receive acute care from geriatricians. However, there has been a heated dispute over how such people are to be selected. The view of the Royal College of Physicians is that this is best achieved by the integration of physicians with a special responsibility for the elderly into general medical teams. Another view is that people above a specified age should be the responsibility of geriatric teams. Such age-related policies have certainly been advantageous in securing elderly people early access to geriatric care on a district general hospital site, and they have been reported as achieving marked success in Islington (Rai, Murphy and Pluck, 1985), Waltham Forest (Mitchell, Kafetz and Rossiter, 1987) and elsewhere. However, these policies have been criticised for "squandering" the skills of geriatricians on elderly people who do not really need them (Young, 1989); an age-related policy can also be seen as ageist, in assigning people between specialties on the basis of their ages, rather than individual needs. Many districts therefore operate selective admissions policies, designed to identify patients who will benefit from geriatric care on the basis of their individual needs.

A recent national survey (Brocklehurst, Davidson and Moore-Smith, 1989) indicated that around thirty-six per cent of districts operated age-related geriatric admissions policies, fifty-eight per cent selective admissions policies, and five per cent an integrated service. The questionnaire sought to ascertain the picture in London: amongst the twenty districts for which information was obtained eleven (fifty-five per cent) operated an age-related policy, and nine (forty-five per cent) a selective policy. However, in six of the districts operating an age-related policy there were elements of selection. In line with the national picture, cut-off ages for geriatric care varied between sixty-five and eighty-five, with seventy-five the most popular option.

Whilst no districts with an integrated policy were identified,

Riverside Health Authority has recently adopted a policy on care of elderly people which will take it in this direction, with the eventual aim of going further, and abandoning geriatrics as a separate specialty:

In the longer term the Riverside model would not have designated consultants with a special interest in the elderly, as all medical staff would be specifically trained in the needs of the elderly as the proportion of elderly people in hospital rises.

(Riverside Health Authority and King's Fund Centre, 1989, p.48)

Irrespective of the admission policy pursued for geriatric medicine, the complexity of the physical problems experienced by many old people makes it essential that there should be good co-operation between the surgical and medical specialists who may have particular expertise in the old person's condition, and the geriatric team who have a wider appreciation of the problems of old age. It is probably a necessary condition for such co-operation that a substantial proportion of geriatric care should be provided in a district general hospital setting, and such a setting is essential if those admitted to the care of geriatricians are to have access to modern diagnostic facilities (Grimley Evans, 1983).

Responses to the questionnaire from acute service general managers revealed that it is now pretty well universal in London health districts that most geriatric admissions are to the district general hospital. Formal liaison arrangements, such as joint ward rounds, between geriatric and orthopaedic teams are widespread; also between geriatric and general medical teams. In some cases there were formal arrangements for liaison with psychiatry: a London-based experiment with a psychogeriatric liaison service demonstrated that this was effective both in improving quality of care for confused elderly people on district general hospital wards, and in securing appropriate permanent care arrangements with a minimum of delay (Fraser and Healy, 1986). Liaison with other specialties used by a large number of elderly people, such as general surgery and ophthalmology, did not generally extend between the possibility of cross-referral: this clearly leaves open the possibility that elderly people attending hospital for treatment within one of these specialties may go without a geriatric assessment from which they would benefit.

The questionnaire to CHCs revealed that the issue causing most concern with respect to the treatment of elderly people was that of communication; particular problems seemed to be associated with conveying bad news, both to patients and relatives:

Patient needed eye treatment at the hospital. The doctor there informed her in a very insensitive way that there was nothing more that could be done to restore her sight. This diagnosis had a very damaging effect on her spirit.

Lady wrote to the CHC about the death of her husband. She was told over the phone by the consultant that the case was terminal.

Several complaints relating to elderly patients not being told they have cancer.

At the discharge symposium a representative of Barnet CHC said that people who had had strokes were often sent home without anyone

having explained what had happened to them, and that this caused feelings of isolation and confusion.

Another area of concern is the question of when to treat and when not to treat. Two particular issues arise here: how to act in a case where the elderly person is confused and incapable of giving consent to treatment; and at what stage one decides that treatment is unlikely to produce a sufficiently good outcome to justify the pain it involves. The latter dilemma is illustrated by the following account presented at the GLACHC symposium on health care for older people:

Last year my mother died after a road accident which broke about half the bones in her body. But she was kept alive for two weeks in intensive care. She wouldn't have wanted to survive in the state in which she'd have come out of it. I'm convinced—though I can't prove it—that the consultant made such efforts because he wanted to see how long you can keep alive a fit old woman who's had such a severe accident.

The usual approach to questions about treatment where the elderly person is unable to give consent is to seek the views of the next of kin, but research conducted in the United States suggests that their views are likely to differ from those of the old person her or himself (Zweibel and Cassel, 1989). An alternative approach suggested by the Law Commission (1991) is the use of 'living wills' in which people set down their treatment choices if they become mentally incapacitated.

Clinical audit, which is promoted in the Government's NHS reforms, is another means of tackling some of these issues. Clearly, however, they are more ethical than technical; for audit to address them satisfactorily it must include lay involvement, and especially involvement of elderly people.

3 Nursing care and rehabilitation

Nursing care and rehabilitation is important for all hospital patients, but especially for those who are elderly. As Dr Peter Horrocks, the former Director of the NHS Health Advisory Service, has noted:

In many hospitals, the technical treatment received by elderly patients is of the very highest standard. What is too often missing is a therapeutic approach which recognises the personal, social and psychological implications of the illness. Restoring and retaining vital functions like mobility, personal care and continence are easily ignored.

(Royal College of Nursing, 1987, foreword)

This was borne out by responses to the questionnaire to CHCs, which revealed that these aspects of acute services to elderly people generated more complaints than any other.

Elderly people are likely to have special nursing and rehabilitation needs in whichever part of a hospital they are treated. This is recognised by the Royal College of Nursing, which emphasises in its guidelines on the care of elderly people in hospital (1987) that "the principles inherent in this report apply wherever elderly people are cared for in hospital, and not simply in designated specialist wards". However, much standard-setting work in the care of elderly people is focused on specialist wards (Hibbs, 1987), and it does seem that the needs of elderly

people are more likely to be overlooked when they are in the minority, a view expressed by Kingston and Esher CHC:

Geriatric beds have been scattered (four on each ward) – members felt staff weren't sufficiently sensitive to the needs of elderly people.

The Royal College of Nursing's guidelines identify the following as targets for care:

- maintaining mobility and independence;
- encouraging elderly patients to take responsibility for their own selfcare and grooming;
- promoting normal sleep patterns without resort to hypnotic medication;
- meeting nutritional needs and promoting mealtimes as a social activity;
- · maintaining an appropriate temperature;
- taking particular care to communicate, bearing in mind that older people may be hard of hearing;
- maintaining a positive attitude to the promotion of continence;
- maintaining a congenial atmosphere in which elderly people are encouraged to maintain their interests;
- holding regular case reviews;
- giving old people the opportunity of a dignified death in line with their cultural and religious wishes.

In recent years there have been widespread moves towards "primary" nursing: the principle that each patient should have an individual nurse to whom they primarily relate. This is generally accepted as a form of good practice, and it is perhaps surprising that it did not receive a mention in questionnaire responses from any source. It may be that in a number of districts difficulties with staffing have limited the extent to which plans for primary nursing have been implemented.

In response to the questionnaire, several CHCs said that their visits had given them cause for concern about the environment in which acute care for elderly people is being provided. Whilst most of these comments related generally to the decor, two CHCs specifically mentioned that wards dealing with a mixed age-group lacked wheel-chair-accessible toilet facilities. Three CHCs also expressed concerns about the lack of occupational therapy on wards dealing with a mixed age-group, and two CHCs had found that elderly patients on these wards did not like being in mixed-sex wards — which in one case involved young men and elderly women sharing a five bed bay.

The care of patients with dementia was a problem on both mixed-age wards and elderly-care wards. Several CHCs noted that the mix of alert and demented patients on elderly wards caused a lot of distress to the alert patients and their relatives. On wards that dealt with a mixed

age-group, there were questions as to whether staff were able to cope with patients with dementia. A contributor to the symposium on health care for older people described the time when her mother, with Altzheimer's disease, was admitted to a surgical ward as "the worst experience of my life":

The staff were terrified of her and had no idea how to manage her. They expected me to be on hand from first thing in the morning till last thing at night.

A high proportion of the complaints which CHCs had dealt with related to nursing care – not surprisingly, as patients interact so much more with nurses than any other service-providers. The aspects which had given rise for complaint were various, with no single item outstanding; however, a couple of issues were referred to in several complaints – problems over the handling of incontinence, and with feeding and diet. The latter had also been noted as an area of concern by several CHCs on visits to elderly care wards, and by Age Concern Greater London in its submission.

Analysis of the complaints does identify one particular "problem" procedure: the transfer of patients between hospital wards, or between hospitals:

Elderly man in hospital, moved between wings without relatives being told. Relatives greatly distressed when they arrived on ward to find him gone and no-one knowing where to.

Daughter phoned early next day to enquire and was told her mother's condition had not changed and on no account would she be transferred that day as planned. When visiting early afternoon found empty bed and was told that she had been transferred that morning.

Elderly woman moved from acute hospital to long-stay geriatric ward without details of her condition accompanying her – result was "dragging about" of patient with a broken hip and lack of care generally.

Transfer between wards was also mentioned in the Age Concern Greater London submission:

The increasing shortage of beds results in frail elderly people being shifted from one bed – or even one ward – to another, resulting in distress and disorientation.

4 Discharge

The Department of Health circular (1989a), which instructed all health authorities to prepare discharge policies, noted that these should give specific attention to the needs of elderly people amongst other groups. Key elements of these policies were to be:

- · clearly defined responsibilities for all staff involved;
- · arrangements for communications with GPs and carers;
- · appointment of keyworkers;
- home assessments;

- liaison with social services over patients who will not be able to return to their own homes;
- informing and consulting patients (and with their consent, responsible relatives) at all stages;
- special arrangements for weekend discharges.

Despite this, dissatisfaction with discharge arrangements has remained widespread, was much in evidence at the discharge symposium, and is borne out by a continuing flow of CHC studies on discharge.

Suggestions have been made that discharges from geriatric departments are better planned than those from other hospital departments (Victor and Vetter, 1988); this is perhaps borne out by an audit of readmissions in Newham which found that a far higher proportion of readmissions of surgical patients was avoidable than was the case for geriatric and medical patients (Clarke and Matus, 1989). Kingston and Esher CHC, in its response to the questionnaire, indicated that it had been pressing for its local general hospital to adopt the discharge policy already used by the specialist geriatric hospital.

Responses to the questionnaire did not identify any districts without a discharge policy, although in some cases the policy was being reviewed. In describing their discharge policies, districts emphasised multidisciplinary working and the use of checklists; only one district mentioned consultation with carers, and none mentioned consultation with patients. This left an impression that the main aim of the policies was to carry through a key task as quickly as possible without hitches, rather than to ascertain and accommodate the wishes of the service user. However, by far the greatest problem with the discharge policies is in the gap between policy and practice; in its submission Age Concern Greater London pointed up the paradox that discharge "is still very bad in places, even where good systems are in place". Discharge was one of the most frequently mentioned subjects of the complaints reported by CHCs; the problems in translating policy into practice were graphically illustrated by one of the contributors to the discharge symposium:

I attended the pre-discharge case conference of a friend who had been in hospital for a long while after a stroke. It was a very good meeting and I came out of it feeling optimistic about the plans that had been made. But when the discharge took place, nothing happened. None of the services that had been promised were delivered.

Some of the major problems about discharge identified at the symposia were:

- Private hospitals do not have effective systems for ensuring that their
 patients receive effective post-discharge support. People who have
 had private treatment often do not have the resources to pay for
 private care on discharge, but have slipped through the net of the
 state system.
- Whilst length of stay in acute hospital has become shorter and shorter, convalescent facilities, especially within the NHS, have practically disappeared.

• People who are being discharged receive very little information about the support that will be available to them; much of the information is presented orally at times when they are under great stress. They need clear written material which they can refer back to.

One of the areas of debate at the symposia was the appointment by health authorities of liaison nurses or placement officers to facilitate discharge. Whilst many people felt that this did represent a significant improvement, others considered that this was an example of the health authority intervening in what had traditionally been a social services responsibility. They felt that accountability to the health authority meant that the holders of these posts were under pressure to clear beds, rather than enjoying the autonomy of the social worker to represent the interests of the patient.

Despite all these difficulties, it would be unfair to suggest that there have been no real improvements. Five of the nine examples of good practice given by CHCs in response to the questionnaire related to improvements that health authorities had made in the handling of discharge. The use of intensive home support following discharge is now widespread. A randomised control trial in Harrow demonstrated that provision of intensive support to people aged over seventy-five for the first two weeks following their discharge from Northwick Park hospital more than paid for itself in terms of reduced readmissions (Townsend et al., 1988). One of the limitations on many of the intensive support schemes is the referral system: whilst geriatricians make regular referrals (and in some cases the schemes only accept referrals from geriatricians), patients in other specialties are unlikely to be referred. The Harrow experiment overcame this difficulty by ensuring that all patients aged over seventy-five discharged to addresses within a specified area were invited to participate in the trial.

A number of hospital discharge schemes started by Age Concern groups in the 1980s using funding provided under the "Opportunities for volunteering" and "Helping the community to care" initiatives have now folded with the expiry of this funding. However, Age Concern Brent's hospital aftercare scheme continues to function successfully. In the co-ordinator's view, operating within the voluntary sector allows the scheme a degree of flexibility which contrasts with her experience of working within the statutory sector.

A study by City and Hackney Health Authority (1990b) of elderly people who had been in acute wards at the Homerton Hospital for over twenty-eight days showed that, although in the majority of cases nursing stafffelt that they still needed to be in hospital, the primary need was far more often for nursing than medical care. This suggests that there is substantial scope for nursing-led services, such as the St Pancras Hospital in Bloomsbury which offers rehabilitation and continuing care. It also gives support to demands for NHS convalescent care, an example of which is provided by the Lambeth Community Care Centre (Wilce, 1988). This community hospital, which was opened in 1985, provides respite, terminal, intermediate and convalescent care for people of all age groups, with medical cover provided by the GPs of the patients. Elderly people discharged from hospital constitute one

of the major user groups. For them, the opportunity to convalesce in a small and friendly facility close to their home, with the continued availability of full nursing care, offers a major psychological boost compared to the relative impersonality of a teaching hospital ward.

One participant at the discharge symposium drew attention to the practice at an acute elderly unit in Stafford of issuing an information pack on discharge. A similar procedure at Manchester involves the provision of discharge booklets to patients soon after their admission to hospital. These become their property, and additional information is written into the booklet throughout the hospital stay, with the patient's permission (Booth and Davies, 1990).

Equity of care

In considering the fairness with which health care is allocated, it is necessary to consider both whether old people are allocated a fair share, and whether the allocation of care between elderly people is equitable.

1 Do elderly people receive their fair share of health care?

As was pointed out in the introduction to this section, ageism remains a potent force in British society. This is evident in the language used within the health service to describe elderly people: individually they are "bed blockers", conjuring up a picture of malevolent interference with the efficient running of hospitals; collectively they are a "rising tide" threatening to engulf us. A recent West Lambeth Health Authority consultation document (1990) followed this fluid metaphor by referring to the need to "decant" elderly people from one hospital to another to allow developments to proceed.

As the clinical conditions and prognosis of elderly people differ substantially from those of younger people, it is difficult to ascertain firm evidence as to whether elderly people are discriminated against in the allocation of health care resources. As has been mentioned earlier, in some cases they may be over-treated. In other cases they may be under-treated: the consensus of the symposium was that when elderly people sought health care, their condition was very likely to be discounted on account of their age. Some evidence for this is provided by the breast cancer screening programme, which has excluded women sixty-five and over, principally on the assumption that they would not respond to screening calls. This assumption has been shown to be false (Hobbes et al., 1990), and there is evidence to show that the out come of treatment of women in the sixty-five to seventy-four age range is not substantially worse than that for women in the fifty to sixtyfour age range. Of course, given the doubts that have been expressed about the whole breast cancer screening programme (Kerrison and Pfeffer, 1990), it may be that this case of discrimination has in fact been of benefit to older women! Henwood (1991), in her exposition on ageism in the health service, draws attention to the exclusion of women aged over sixty-five from the cervical cancer screening programme.

Fentiman (1990) has pointed out that although about half of all new malignancies occur in people aged over seventy, people in this age group

are routinely excluded from trials of new cancer treatment. He points out that the decision to leave cancer untreated is often based upon a "common prejudice... that cancer is a more indolent disease in the elderly", for which there is no evidence. Likewise, judgements about whether elderly people will be able to withstand treatment are often based simply upon their age, rather than on their individual condition.

The key problem in tackling discrimination against older people in health care is the lack of any satisfactory criteria for monitoring the benefit people obtain through treatment. Whilst the concept of "quality adjusted life years" (QALYs) has gained fairly widespread currency, a view expressed at the symposium was that these were inappropriate in assessing the value of services to elderly people, for whom quality is likely to be very important and life years of much less significance. It may also be noted that uncritical use of QALYs implies discrimination against older people who, although they may gain a similar benefit from an operation to a younger person, will normally expect to enjoy this benefit for many fewer years.

2 Is allocation of health care between elderly people equitable?

Whilst there are in any health system examples of individuals who obtain more or less than their "fair" share of care, this study is concerned with whether such unfairness exists in any systematic way, leading to discrimination against particular groups.

Race

The aspect of inequity which aroused by far the most concern at the symposium was discrimination on the grounds of race. Areas of concern raised included the failure of service-providers to offer or make use of interpreting services, incorrect assumptions about the availability of family support, lack of sensitivity within hospital to minority cultures, and lack of respect for therapies widely used by particular minority ethnic groups. These areas of concern were also reflected in the black and minority ethnic symposium.

Voluntary migrant groups are likely to be disproportionately healthy, as people with severe health problems are unlikely to uproot themselves from their country of birth; this was reflected in early data on the health of post-war immigrant groups in Britain. However, as the black and minority ethnic people who came to this country in the 1950s and 1960s have aged, evidence of a number of widespread health problems has emerged. Amongst people of African/Caribbean origin, there are high rates of stroke, diabetes and hypertension, whilst amongst Asian people there is a high incidence of heart disease and osteomalacia. A survey of the health of different ethnic groups in Birmingham found that those of minority ethnic groups experienced a similar level of self-reported ill health to a significantly older white group (Blakemore, 1982), whilst the results of a study of GP consultation rates demonstrate that a sharp age-related increase in the frequency of consultation occurs about ten years earlier in the African/ Caribbean and Asian groups studied than in the white group (Balarajan,

Yuen and Raleigh, 1989). Some efforts have been directed to identifying the specific causes for high incidence of illnesses in minority ethnic groups, but Donovan (1984) has argued that this should be seen in the context of the social and economic hardship that black and minority ethnic groups experience. A further point which may explain some of the apparently earlier ageing is that many Asian immigrants understated their age at the time of entry to Britain in order to improve their employment prospects, and now have this registered as their "official" age. One result is that rigid age barriers may exclude some people from minority ethnic groups from using services which are appropriate to their needs.

Evidence on the use of health services by older people in minority ethnic groups (Norman, 1985) suggests that black and minority ethnic people are more likely to use GP services than the white population, but much less likely to receive community health services, especially within the Asian communities. African and Caribbean people, especially women, are more likely to go to hospital but Asian people are less likely. Although there is no firm evidence, it seems likely that people of minority ethnic groups are more likely to seek private consultations than white people with an equivalent income.

One of the problems which people from minority ethnic groups experience is a lack of information about services. This is particularly acute for those groups whose language is not English; within these groups it is women, and particularly older women, who are likely to have least knowledge of English. But problems with communication persist even when contact has been made. Many districts have little provision for interpreting. Even where services exist, there may be problems in obtaining access. Haringey CHC points out that the linkworkers based at the North Middlesex Hospital are only available from nine in the morning to five in the evening, and will only be called in on the initiative of the ward staff. Ward staff may not take such an initiative, as is illustrated by the following complaint which originates from a district with a well-established interpreting service

Elderly person in acute hospital did not speak English as a first language. Initially labelled as difficult and uncommunicative, then deaf. An interpreter would have told a different story.

The non-availability of interpreting services is important not only in its own right, but also because it demonstrates that, as the Age Concern Greater London submission put it, "the hospital is remote from the community it serves". A survey of the experiences of Asian elders in Brent found that "inpatients expressed a dread (the word is no exaggeration) of hospital admission" (Moledina, 1987). Amongst the problems minority ethnic elderly people have experienced in their use of hospitals are:

- difficulty in obtaining transport for escorts on the ambulance service (even when escorts were acting as interpreters);
- not knowing how hospital staff expect patients to behave, and not receiving any explanation of this;

- difficulty in obtaining appropriate food;
- lack of space or facilities for religious practices;
- · lack of appropriate washing facilities;
- rules on visiting times and numbers which conflict with cultural and family norms;
- · intimate examinations of women by male doctors.

Possibly the most damaging cultural clash experienced by ethnic minority elders is in the loss of status that they experience (Standing Conference of Ethnic Minority Senior Citizens, 1986). The majority were born in countries where elderly people were treated with respect and even reverence; in Britain they are not.

The fact that older people from minority ethnic groups are likely to live with younger generations and are likely to have higher expectations of their family as care providers has been used to "explain" the very low level of community health and social services they receive (Donaldson, 1986). However, the nature of the housing stock in Britain, and especially in London, means that multigeneration patterns of living can survive only with severe overcrowding, and are rapidly becoming less widespread; in any case, expecting families in minority ethnic groups to provide a degree of support to their older relatives that is not expected of white families is clearly discriminatory and will serve to perpetuate the disadvantages black and minority ethnic people experience in the labour market. Furthermore, those elderly people who do live alone may well have absolutely no relatives living in this country; a representative of the Chinese community who attended the symposium pointed out that this applies to many of the elderly Chinese men living in Central London who have worked in the catering trade.

An issue of particular importance to the Chinese and Vietnamese communities, and also of importance to other minority ethnic groups, is the relationship between Western medicine and other therapies such as acupuncture and herbalism. Whilst many elderly people come from countries in which there is co-operation between therapists in the different traditions, and it is not uncommon to encounter practitioners skilled in both Western medicine and traditional therapies (West Lambeth Health Authority, 1988), they have found from British medical practitioners a predominant view that therapies from other traditions are little more than quackery. They perceive this as a racist rejection of their own experience of the benefits of other therapies, which they believe to be particularly valuable in alleviating the discomfort associated with long-standing conditions of old age such as rheumatism. A project which is going some way to counteract these problems is the Hoxton health group in Hackney, which is attempting to make available a range of alternative and complementary therapies within an NHS setting.

Gender

Statistics for usage of hospital services (DHSS and OPCS, 1987) reveal a markedly different pattern of use between older women and older men. Women are less than half as likely as men to be admitted for general surgery or urology; they are nearly fifty per cent more likely than men to be admitted for trauma or orthopaedic surgery. Women are about a third less likely than men to be admitted for general medicine; they are also marginally less likely to be admitted for geriatric medicine, but because their average length of stay is one and a half times as long as that of men they occupy far more beds.

Some of these differences, especially in the surgical specialties, can at least be partially explained by differences in the health problems experienced by women and men. The longer length of stay by women can certainly be explained largely by the fact that women are far more likely to be living on their own. This may be compounded by professional assumptions that an elderly woman cannot expect as much support from her husband as an elderly man can from his wife. Another factor which cannot be discounted is that doctors are better at identifying specific health problems in men; an unhealthy old woman is more likely to be seen as stereotypically "frail" and in need of geriatric care.

Class

Life expectancy is closely related to social class, although the extent of difference between classes is substantially less in people who have reached retirement age than in younger age groups (Black, Townsend and Davidson, 1982). Whilst there is no firm data on differential use of health services by older people in different social classes, there is widespread anecdotal evidence that people from the less affluent social classes are more likely to be patients of geriatric medical services, whereas those from the more affluent classes are more likely to receive treatment from a condition-specific specialty, although the relocation of acute geriatric services to district general hospital sites is felt to be lessening the difference. As with gender-related differences in treatment, this may be due to stereotypical professional views of older people from the less affluent classes.

Sexuality

It is important to remain alert to the possibility that there is discrimination against older lesbians and gay men within the health service; incorrect assumptions about relationships with regard to caring or bereavement are a particular danger.

Acceptability of services

Whilst there has been much writing about good practice in the acute care of elderly people, there have been very few systematic attempts to ascertain the views of elderly people on this subject. Hospital admission is not surprisingly seen by elderly people as a highly undesirable experience: a study by Salvage has shown that admission to geriatric hospital or geriatric wards is perceived with particular distaste (Salvage et al., 1988). This was reflected in a complaint reported by Croydon CHC, in which a patient, with her husband's support, wished to be admitted to an acute hospital bed, whilst her GP felt that it was more appropriate for her to be admitted to a geriatric hospital.

Elderly people's unfavourable views of geriatric care are based on a long history of neglect and maltreatment in geriatric hospitals and wards (Robb *et al.*, 1967); as any scrutiny of Health Advisory Service reports demonstrates, inhumane attitudes to the care of elderly people persist amongst some service-providers. As one participant in the symposium put it: "A lot of elderly people are terrified of the care that they need."

More insidious than the now relatively isolated cases of brutality is the continuing low status of work with elderly people. Geriatric consultants are less likely than consultants in other major specialties to be in receipt of distinction awards. The continuing high proportion of new consultants appointed who are overseas-born is an indicator, not of a positive attitude to equal opportunities, but of the unpopularity of geriatric medicine with graduates of British medical schools. Indeed, a series of surveys of medical students from the mid-1970s to early 1980s demonstrated that less than one in two hundred medical students regarded geriatric medicine as their first choice of career, although during this period almost five per cent of new consultant appointments were in geriatrics (Ellin, Parkhouse and Parkhouse, 1986). Nurses caring for elderly people are likely to be less qualified than those in other acute wards. The new nurse education curriculum established under Project 2000 does not contain any specialist option on care of the elderly: whilst this omission was supported by the Royal College of Nursing on the grounds that nursing elderly people should form part of the basic course, Christine Hancock (1990) has expressed concern that it may lead to reduced attention to the needs of elderly people.

There have undoubtedly been quite a few positive moves in the past decade: geriatric units within district general hospitals have given geriatricians much higher status amongst doctors; it appears that care of elderly people is the most common career specialism of graduates emerging from degree courses in nursing (Kemp, 1988). However, substantial problems do remain. It has been suggested that one of the problems in attracting professionals to work with older people is the scarcity of positive images of old age (Biggs, 1989). This perhaps chimes with a comment made at the symposium, that many older people would be happier if more of the nurses caring for them were older. Yet it has to be acknowledged that old people too are affected by the predominantly negative images of old age. One of the features of Salvage's study (1988) was that the commonest reason given by elderly people for not wanting to be on a geriatric ward was that they did not want to be amongst old people. If care for elderly people is to be regarded as other than a second-class service, it is necessary that society at large must begin to regard elderly people as other than second-class citizens.

Efficiency of services

In attempting to maximise the efficiency of their services, health authorities may be concerned either with "technical" efficiency (providing the maximum level of service for a given cost), or "target" efficiency (ensuring that services are directed to those most in need). Sometimes searches for efficiency lead to nonsense: one case was raised at the symposium on health care for older people of an elderly person who received a delivery of incontinence pads that were the wrong size. When her carer questioned about this, she was told that the health authority was trying to use up a consignment. Sometimes efficiency for a health authority represents gross inefficiency for the system as a whole: a clear example of this may be found in the incentive health authorities have to discharge people into nursing homes funded by social security payments, rather than to meet the substantial, but possibly lesser, costs of the support that would enable such a person to manage at home – this anomaly should be rectified when the Community Care Act is eventually implemented in April 1993.

It has to be acknowledged that there is often a degree of coincidence between the health authority's view of economic efficiency, and the consumer's view of desirable services. The aims of minimising hospital admissions and readmissions, and length of stay in hospital are all indicated if service efficiency is to be maximised; they are also in line with the wishes of most older service users. However, this should not obscure the fact that a consumer's assessment of costs differs significantly from that of a health authority. The following are a number of examples of such differences.

- Waiting lists: The costs to a health authority of a waiting list are to be measured in the administrative inconvenience of managing a waiting list effectively, and the extent to which treatment is more difficult on patients who have waited for a long time. For a patient, there is the additional cost of the discomfort he or she experiences whilst waiting; a cost that the health authority experiences only indirectly through political pressure.
- Cancelled admissions: The cost of cancelled admissions to a health authority is to be measured in the administrative costs of cancellation, as well as the greater likelihood that patients will not attend when firm arrangements for an admission are made. For a patient, there is the additional cost of the arrangements that have been made prior to a cancelled admission; again these costs affect the health authority only through political pressure.
- Early discharge: The costs to a health authority or provider unit of inappropriate early discharges are reflected only in the increased likelihood of readmission, which has been consistently used as the indicator of the success or failure of discharge policies. For the patient, the stress of trying to cope at home while not sufficiently fit to manage is itself a cost. It is noticeable that although surveys of elderly people discharged from acute hospital consistently show that the majority think their length of stay was about right, they equally consistently show that far more people believe they were discharged too early than believe they were kept in too long.
- Use of non-local services: A health authority or GP fundholder may regard services outside the locality as a "good buy"; such calculations

are unlikely to take account of the additional cost of travel, in time, money and stress, to patients and their friends and relatives.

• Community services: A health authority's assessment of the efficiency of community services is likely to be determined primarily by the extent to which they prevent breakdown of home caring arrangements, and admission to hospital; for the service user, the key efficiency measure is the extent to which they improve the quality of life.

In the absence of accountability to service users, and given the very limited political "clout" of elderly people, it is likely that the nature and volume of services will be determined more by the health authority's view of efficiency than the service user's.

It will be noted that costs to a health authority are fairly readily quantified in financial terms; costs to the consumer much less so. The dominance of financial measures in the assessment of efficiency does seem to lead to undervaluing labour that is provided without charge. This applies most markedly to labour provided by carers of elderly people: at the symposium there was general assent to the view that carers were undervalued by service-providers, and a feature of the complaints reported by CHCs was a reluctance of service providers to consult with carers, especially over discharge. It also applies to the labour of volunteers. A couple of examples were given at the symposium, which are perhaps symptomatic: Age Concern Bexley has a scheme using volunteers to cut toenails, but the health authority's chiropodists have difficulty in finding the time to train volunteers; a volunteer driver had had his car wheelclamped on hospital grounds whilst he was picking up a patient!

CHAPTER

7

Looking to the future

Demographic trends

An analysis of the overall trends in London's population (Champion and Congdon, 1988) suggests that the long-term decline in population has been halted, and that something of a rejuvenation of the population is taking place. Looking more specifically at the elderly population, over the next ten years London will see a decline of approximately ten per cent in population aged over sixty-five and approximately seven and a half per cent in population aged over seventy-five. In the numerically much smaller group of people aged over eighty-five, there will be an increase in population of around fifteen per cent. There will be a particularly sharp increase in the number of men aged over eightyfive, of about twenty-four per cent (London Research Centre, 1989, Table 25). Assuming age and gender-specific bed-use rates remain constant, decline in population aged over sixty-five in the next decade would result in reduced demand throughout London of around 250 beds in geriatric medicine, 160 beds in general medicine, 125 beds in general surgery and urology, and sixty-five beds in trauma and orthopaedic surgery (ibid.; DHSS and OPCS, 1987). Of course, the assumption of constant rates of use is quite unrealistic: the figures are cited not to justify any reduction in bed numbers, but to indicate that over the next decade population change will offer some scope for improving services to elderly people within existing resources.

Perhaps the most dramatic change in London's elderly population over the next ten years will be a very rapid increase in the number of elderly people in black and minority ethnic groups. In 1984-86, around fourteen per cent of people in these groups were aged between fortyfive and retirement age, with just three per cent above retirement age (Shaw, 1988); figures for the London population as a whole were nineteen per cent and seventeen per cent respectively. The figure for the African/Caribbean communities, which are particularly concentrated in London (Haskey, 1991), were still more marked: twenty per cent aged between forty-five and retirement age, just three per cent above retirement age. By the end of the decade, although there will still be relatively few minority ethnic people aged over seventy-five, the proportion above retirement age will no longer be substantially less than that of the white population. Whilst the impact on services will depend upon the extent to which indications of earlier physical ageing amongst people from black and minority ethnic groups are borne out, it is clearly essential that priority is given to making services responsive to the needs and experiences of people from different racial and cultural groups.

Service trends

Over the past ten years there has been a consistent reduction in the number of hospital beds available to elderly people, combined with an equally consistent increase in the number of admissions and discharges. Health authority plans generally envisage a continuation of the process of shortening lengths of stay, leaving more care to be provided in the community.

Health authority involvement in long-stay care has reduced dramatically as a result of the very strong financial incentives that exist for such care to be provided in private nursing homes. Whilst the NHS and Community Care Act will reduce the availability of social security funding for private nursing home places, it certainly offers no incentive for the NHS to increase its role in the field; given current trends and plans it is likely that by the end of the decade the NHS role as direct provider of continuing inpatient care for elderly people will have effectively ceased.

Whilst the quality of care in private nursing homes is very mixed, and there are grave doubts as to whether sufficient resources have been allocated to community services to enable them to cope with the extra demand, there is no doubt that acute elderly care units have gained resources over the past decade. These resources have not been reflected in an increasing number of beds, but in their increased concentration on more expensive district general hospital sites. There does appear to be a consensus that these moves have borne dividends, and over the next decade there is likely to be a consolidation of the move to district general hospital-based acute elderly care units, which is already almost complete. Responses to the questionnaire indicate that these units will increasingly adopt age-related policies although, as noted, Riverside health authority's plans point in an entirely different direction, towards integration of elderly care into other specialties.

Whether there have been increases in spending on other acute services used by elderly people is a matter of heated political debate: it is certainly clear that during the past decade there has been a substantial increase in waiting lists for surgery. Such a political "head of steam" has developed on the issues of waiting lists and poorly planned discharges that they are now receiving considerable attention from health authorities: it may now be time to direct attention to other indicators of quality, or the lack of it.

Effects of the NHS reorganisation

So far there is little firm evidence of the impact of NHS changes. This section will consider the likely impact of the changes on the key "actors" in the post-reorganisation NHS: GPs, health care purchasing authorities, and service-providing units or trusts.

GPs

The new contract for GPs introduced a duty to screen people aged over seventy-five. Around ninety-five per cent of people in this age-group in any case sees their GP at least once a year; opportunistic screening

of these people may well identify unmet needs. However, unless attempts to call people for screening are combined with a much more positive approach to promotion of health in older people than is at present in evidence, they may simply result in GPs spending their time carrying out a set of routine procedures on healthy elderly people, rather than devoting their time to elderly people who are ill. Fears have been expressed that the duty to screen will lead to GPs removing elderly people from their lists.

An issue which has come to rapid prominence following the implementation of the changes is the apparently superior purchasing power enjoyed by fundholding GPs for their patients. One area of concern whilst the changes were being planned, which has never been fully resolved, was that the constraints of budgets would make fundholding GPs less willing to register elderly, and particularly frail elderly, patients. If this concern is born out, then the successes of fundholding GPs could represent a form of discrimination against older people.

Health care purchasing authorities

The changes have forced health authorities to address the question of what quantity and quality of service their district residents are to receive. As responses to the questionnaire indicated, the detail in which this question has been addressed varies considerably. It does, however, appear to be uniform that the specification of quantities of service is being done simply on a specialty basis, without any indication of the allocation of service between population groups. Thus, if pricing policies do not take proper account of the extra needs of older people, this will present an incentive for provider units to discriminate against them and in favour of younger people who are likely to recover more quickly after treatment.

In specifying the quality of service that they expect provider units to deliver, responses to the questionnaire suggest that health authorities are issuing contracts that include a number of very specific requirements (for example, the maximum waiting time that is acceptable in an outpatients department, the level of seniority of the doctor who should see a patient on a first appointment) and some that are much more general (for example, "all care should be provided in as comfortable and as personalised a setting as possible"). Whilst it is likely that the degree of expertise in drafting contracts will improve over coming years, it is clear that the contracts presently issued will only be effective in maintaining quality if there is good will on all sides.

Broadly speaking, methods of monitoring outlined in response to the questionnaire fell into the following categories:

- regular reports of a specified format from service providers;
- visits to premises where service is provided;
- study of summaries of complaints;
- · surveys of patients, carers and general practitioners.

There were very few references to the potential role of organisations and groups of service users, and of advocacy schemes. Such approaches

are necessary if the critical views of users are not to be concealed by the acquiescence that dependent individuals almost always express when faced with individual questioning about the organisations on which they rely.

In the first year following the new legislation health authorities have followed departmental guidance in placing contracts with providers who have been used by residents of their districts in previous years; in future years they are more likely to "shop around" for the "best buys". This could result in patients from a single area being expected to make use of different hospitals for different services; elderly people who have complex conditions would be likely to miss out in such circumstances. Such problems are by no means new to elderly people in London, who have often been in the catchment areas of different hospitals for acute geriatric and other acute care (Morton, 1987), but they do threaten to raise the confusion to a new level. If purchasing strategies result in patients having to travel outside their home area, this may also disadvantage elderly people. At the symposium, a representative of an Asian community group from Southall reported that members of the group who had travelled to Moorfields for eye operations had been less satisfied than those who had had treatment locally, in spite of the clinical excellence of the Moorfields service; they felt uncomfortable in what was for them an alien environment.

Service-providing units and Trusts

One of the fundamental worries about the changes in the NHS is that they will, in the words of the Royal College of Nursing, "divide health care". Essentially, the fear is that with the emphasis on the creation of autonomous units, destined eventually for Trust status, rather than on a corporate district, the notion of a single comprehensive health care service will be lost, with each unit taking responsibility only for that element of the service it has to provide. It is, of course, very early days to say whether this gloomy hypothesis is justified, but a startling piece of evidence in support of it came from a questionnaire response from a service provider unit, on the point of becoming a Trust. In response to a question about liaison between geriatricians and consultants in other specialties, the respondent wrote:

Up to 31.3.91 no problem as care of elderly physicians can bring their patients into intensive care unit/coronary care unit, and medical specialties treated care of elderly patients. [Hospital] now a Trust and care of elderly part of a directly managed unit. We are now faced with medico-legal problems, two computer systems, etc., etc.

It is to be hoped that this is not a sign of things to come.

ANNEX

Three questionnaires were circulated to all health districts wholly or partly in London, one addressed to acute service general managers, one to health care purchasing authorities, and one to CHCs. Response rates to these questionnaires were, respectively, seventy-five per cent, twenty-five per cent and forty-eight per cent. Some response was received from at least one source for all districts but one, although in only three districts, was a response received from all three sources. One or two very late responses were received, which means that a few figures in this annex differ slightly from those given in the main text.

1 The questionnaire to acute service general managers

This questionnaire was dispatched in March 1991, and was addressed to acute service general managers for each of the districts – some of the services covered have now acquired Trust status. One reminder was sent. Twenty-two responses were received, covering services provided by twenty-one different districts (two responses being received from one district with two major hospitals). In most cases it appeared that responses had been completed within the geriatric department/department of medicine for elderly people.

Question 1

Respondents were asked to indicate whether their admissions policy for elderly people requiring acute medical care was age-related, needs-related, or integrated.

Twenty districts responded to this question. Six districts operated an admissions policy that was purely age-related, and nine districts one that was needs-related, with age considered only as an indicator of need. In the remaining five districts there appeared to be a compromise between the two policies, with some admissions being age-related and others needs-related. More details of responses to this question are given on p.86.

Question 2

Respondents were asked whether people receiving acute inpatient care from geriatricians/physicians with a special responsibility for elderly people were likely to be admitted to a mixed-age ward in a general hospital, a specialist ward in a general hospital, or an acute ward in a geriatric hospital.

Twenty-one districts responded to this question. All districts had made some use of specialist elderly care wards within the general hospital, and in fifteen of the district all or most admissions were to

these wards. In three districts some use was made of specialist wards and some of mixed age wards, all within the general hospital; in one district some use was made of a specialist ward within the general hospital, and some in an acute ward in a geriatric hospital; in one district most admissions were to an acute ward in a geriatric hospital; one district used all three options. There was some evidence that those districts operating purely age-related admissions policies were more likely than others to rely entirely on specialist wards within a general hospital.

Question 3

Respondents were asked about liaison arrangements between geriatricians/physicians with a special responsibility for elderly people and consultants in other medical specialties.

Twenty-one districts responded to this question. Sixteen districts said that there were such arrangements, although in seven cases these did not extend between personal contacts and the opportunity to make cross-referrals. In the nine districts citing formal liaison arrangements, these ranged from regular meetings to joint clinical teams. Of these districts, four referred specifically to liaison with general physicians, and two with general psychiatrists.

Question 4

Respondents were asked about liaison arrangements between geriatricians/physicians with a special responsibility for elderly people and consultants in other medical specialties.

Twenty-one districts responded to this question. Seventeen districts said that such arrangements existed: in six cases they referred only to the opportunity for cross-referral, but in eleven cases they reported particular arrangements for liaison with orthopaedic surgeons. No specific arrangements for liaison with other surgical specialties were mentioned.

Question 5

This question was intended to ask about any arrangements that existed to lessen the trauma of admission for elderly people. Unfortunately, it was somewhat ambiguously worded, and was widely interpreted as asking about the availability of planned admissions to elderly care wards. Thus, no inferences can be drawn from the responses.

Question 6

Respondents were asked about facilities or procedures for meeting the needs of elderly people in the accident and emergency department.

Nineteen districts responded to this question. Nine said that there were no special facilities or procedures, and a further four mentioned only the availability of referral to the geriatric/ medicine for the elderly team. Three districts mentioned special arrangements for following up elderly people discharged from the accident and emergency department, and two districts referred to specific policies covering discharge of elderly people from accident and emergency. Only one district mentioned any facility within the department itself—the availability of

sheepskin or Spenco mattresses to prevent bedsores amongst elderly people lying on trolleys.

Question 7

Respondents were asked about policies for arranging the discharge of elderly people.

All of the seventeen districts which responded to this question confirmed that they did have a discharge policy. Twelve gave some information about the policy. The questionnaire did not allow space for a comprehensive description of the policy, but the aspects mentioned do perhaps give an indication of the elements of the policy which respondents considered most important. Eight mentioned that it involved multidisciplinary working, and five that there was a checklist to be followed. Five referred to the availability of specific health authority staff with responsibilities either to facilitate discharge or to find places in residential and nursing homes. Three districts mentioned that they arranged for pre-discharge home visits, and four referred to post-discharge facilities. Three districts referred to communication with relatives (one specifically mentioning consultation) and one to communication with patients.

Question 8

Respondents were asked whether their units operated any "hospital at home" or early discharge schemes.

Eighteen districts responded to this question. Thirteen operated no such schemes. Of the five which did mention schemes, four related to early discharge, and one to terminal care.

Question 9

Respondents were asked to cite any aspects of their unit's service which they considered to be examples of good practice.

In all, twenty-nine examples were cited. No overall trend emerged, and it proved quite difficult to categorise the examples given; some are mentioned in the main text. There were six mentions of the quality of specialist acute services for elderly people (both the staff team and the facilities), and three mentions of the ease of access to these services. There were four mentions of good liaison arrangements between acute elderly and other services, and five mentions of non-acute services. Three districts referred to discharge arrangements, two to audit arrangements, and two to professional training and leadership. Three districts gave examples which fell into none of the above categories.

2 The questionnaire to health care purchasing authorities

Just seven responses were received to the initial questionnaire, and in view of this disappointingly low rate of response no reminders were sent. It is probable that the low rate of response is attributable to the extreme pressures under which health authority officers responsible for purchasing were working in March and April 1991. However, at least one response was received from each region, and there was a reasonably

representative mix of inner and outer London, and teaching and non-teaching districts. Several of the responses gave a great deal of detail, making them a rich source of data, if somewhat incomplete.

Question 1

Respondents were asked whether they were aware of any deficiencies in the quantity of acute services provided to elderly people within their districts.

Four were not aware of any such deficiencies; amongst the three who did indicate concerns no common themes emerged.

Ouestion 2

Respondents were asked whether they had any concerns about the quality or appropriateness of acute services provided to elderly people within their districts.

One respondent had no such concerns; the remaining six indicated fourteen concerns between them. Problems with discharge arrangements were mentioned by three respondents; over-use of institutional rather than community care by three; the absence of an age-related admissions policy for acute elderly services by two. No other concerns were mentioned by more than one district.

Question 3

Respondents were asked whether the contracts they were issuing specified quantities of service to be provided to older people.

It appeared that all districts were issuing contracts based on specialties, rather than client groups.

Question 4

Respondents were asked whether the contracts they were issuing specified standards for the quality and appropriateness of services provided to older people.

All respondents said that their contracts did specify standards, and some gave a great deal of detail on these standards. There was a mix between those standards which were highly specific and clearly measurable, and those which were much more general. Those issues mentioned by three or more respondents were: access to services (waiting lists, waiting times and cancelled admissions), mentioned by four respondents; behaviour towards patients (courtesy, provision of information, appropriate arrangements for seeking consent), mentioned by four respondents; and discharge arrangements, mentioned by three respondents. Other issues raised were the need to provide an integrated service; sensitivity towards ethnic and linguistic minorities, reduced reliance on institutional care, the seniority of the doctor patients would see on their first contact with the service, the use of an age-related admissions policy, communication with GPs, provision of information to relatives, and efficiency in the handling of medical records.

Question 5

Respondents were asked about arrangements for monitoring the quantity, quality and appropriateness of care provided to older people.

Six of the seven districts gave details in response to this question. All of these districts mentioned activity data and/or audit reports to be supplied by the provider; five districts mentioned surveys or other ways of canvassing the views of services users; four districts mentioned monitoring of complaints. Other monitoring methods mentioned were visits (two respondents), exception reporting by GPs (one respondent) and consultation with the CHC (one respondent).

Question 6

Respondents were asked about proposals for improving the quantity, quality or appropriateness of services provided to older people.

The department of health guidance on "steady state" contracting meant that no districts had proposals for changes in the quantity of service. All districts had some proposals for improvements in the quality of services, but it was not possible to discern any theme in these proposals.

3 The questionnaire to CHCs

The questionnaire to CHCs was sent out simultaneously with the other questionnaires. One reminder was sent, and fourteen responses were received.

Question 1

Respondents were asked what proportion of complaints they dealt with about acute care related to older people (with a suggestion that they should consider people who they estimated were aged seventy-five or over as "older"). They were also asked what proportion of these complaints related to waiting lists, clinical treatment, care in hospital, discharge from hospital, and other factors.

Thirteen CHCs responded to this question. Whilst several stressed that their figure was a rough estimate, eleven came within the range twenty per cent to thirty-five per cent. Whilst little confidence can be placed on the precise figures, it does suggest that complaints about the care of elderly people represent a substantial, but not overwhelming, proportion of CHCs complaints caseloads, roughly in line with the proportion of people admitted to hospital who are elderly.

Few indicated any complaints in the "other" category. Proportions were clearly very rough estimates, but an averaging of the rankings suggested that most complaints were about care in hospital, followed by clinical treatment, then discharge arrangements. Waiting lists accounted for far fewer complaints than the other categories.

Question 2

Respondents were asked to give anonymous summaries of two recent complaints which they felt were illustrative of the problems elderly people experienced in using acute services.

Twelve CHCs gave between them twenty-three examples. Several of these examples were complaints about more than one aspect of care. Seven complaints were about the standard of care in hospital (two referring to accidents on the ward, and three to feeding arrangements), five were about discharge arrangements, four were about

communication of the diagnosis, and three were about transfers between wards or hospitals. Several other issues were mentioned, but non arose in more than one example.

Question 3

Respondents were asked if CHC members on visits to acute hospitals had noted any concerns about the care of elderly people on wards dealing with a mixed age-group.

Eleven CHCs responded to this question, nine indicating that they had concerns. Six CHCs were worried about a lack of appropriate facilities for elderly people, and three had more general concerns about the decor. Mix of sexes, lack of staff skills in dealing with older people, and discharge arrangements were each mentioned by two CHCs.

Question 4

Respondents were asked if CHC members had noted any concerns on visits to acute elderly care wards.

Twelve CHCs responded to this question, ten indicating that they had concerns. Four CHCs were concerned about food and feeding arrangements, three about the lack of appropriate facilities, and two each about the mixture of patients with and without dementia, terminal care, and the lack of information available to patients and relatives.

Question 5

Respondents were asked if the CHC had expressed any other concerns about acute care of elderly people.

Eleven CHCs responded to this question, ten of which had expressed concerns. Six referred to discharge arrangements, and three to planned changes in service. No other concerns had been raised by more than one CHC.

Question 6

Respondents were invited to give any examples of good practice within their districts.

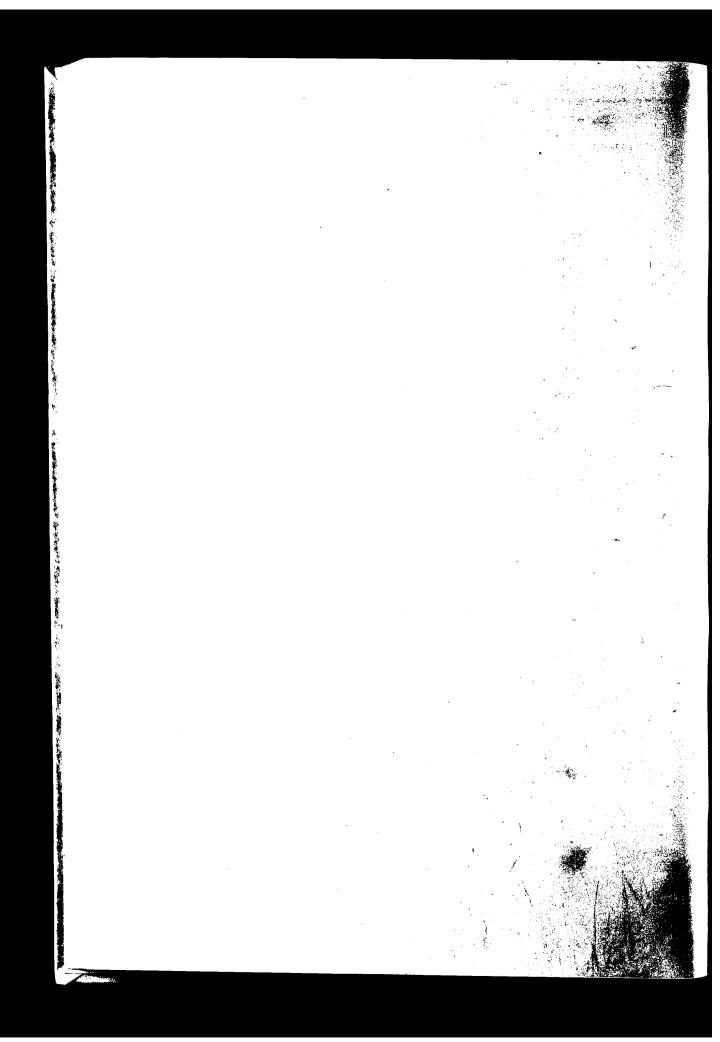
Eleven examples of good practice were given by nine CHCs. Five related to discharge arrangements. No theme emerged from the other examples.

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Part 3

ACUTE CARE FOR SINGLE HOMELESS PEOPLE
A study by the Medical Campaign Project





CHAPTER



Introduction: Homeless people and health

art 3 of this working paper will examine the extent to which London's health services are responding to the needs of single homeless people and the implications this has for future policy development and service planning. It will show how homeless people are among the most vulnerable users of health services, yet their ability to access basic health care facilities and to exercise their right to quality services is extremely limited.

The study is based on the premise that homeless people do not have "special" or different needs from the housed population, but that they have fewer of their needs met. Both the structure and organisation of health services and the attitudes of service providers act as obstacles preventing this group of users from gaining access to services and receiving appropriate treatment and care. In the words of the Medical Campaign Project (Report, 1988):

We assert the right of single homeless people to decent, appropriate and good quality health care, with the same rights of access as those who are securely housed. The health service must ensure that people who are homeless can exercise this right.

Homelessness in London

In recent years there has been a marked increase in single homelessness throughout the country (Faculty of Public Health Medicine, 1991), and this can be seen in rural areas as well as in the inner cities. In London the situation is particularly acute. As the capital city it acts as a magnet for many people who come looking for jobs and the rise in the number of street dwellers has made this aspect of homelessness a visible part of London life.

This is perhaps most obvious in central London, partly because this is where the main railway stations are, and also because there exists a number of known sites such as the Bullring and Lincoln's Inn fields where single homeless people have tended to congregate. These sites also tend to be where voluntary support such as soup runs is given; concentrations of homeless people reflect patterns of provision of this kind, where it exists.

In March 1991 the Medical Campaign Project contacted a range of agencies across London to establish a London-wide picture of single homelessness. Agencies in outer London boroughs were concerned that there is an increasing number of visibly homeless people in areas where this apparently had not existed before. This suggests that homelessness is a growing issue affecting all London districts and not restricted to particular areas.

It is also the case that homelessness has become an integral part of

inner city life in general, and particularly in areas of high economic and social deprivation. Yet much of this homelessness is hidden – that is, people are staying with friends or relatives, often in overcrowded and substandard accommodation, rather than on the streets or in hostels. There is clearly an urgent need to address the health care needs of these people as well as the needs of the more visible homeless population.

Methodology

This part of the working paper documents the experience of homeless people and the effects of homelessness on their health status and their ability to exercise their right to quality health care. It is based on information provided by workers from a range of different homeless agencies who have had experience of helping clients to access services, and where possible from homeless people themselves. This information was obtained through extensive personal contact, symposia organised by GLACHC, and a London-wide conference organised by the Medical Campaign Project, held in March 1991. Additional information was obtained from interviews with staff at a central London teaching hospital.

A number of reports have already been written about the health needs of homeless people. These are referred to where appropriate. Using these sources of information it has been possible to draw up a picture of the way in which health services are currently responding to the needs of single homeless people. Where applicable models of good practice are highlighted and recommendations are made for the future.

Part 3 starts by attempting to define homelessness. Homeless people are shown to be not only at greater risk of physical and mental ill health, but also to have poor access to health care services. The existing health care package available to homeless people is described, from primary care to accident and emergency services, hospital admission and discharge. This is followed by a study which looks specifically at the accessibility and appropriateness of mental health services for homeless people in London.

In undertaking this research it quickly became clear that acute services cannot be seen in isolation from the provision of primary, preventive and community care services. As this study will show, homeless people have very limited access to basic health care facilities. Moreover the lifestyle imposed by being without a home makes it difficult for homeless people to maintain good health, to be contacted for treatment via a waiting list, or to receive community care. Therefore this section of the working paper focuses on the barriers preventing homeless people gaining access to acute hospital services and the difficulties that arise in arranging care for someone without a secure home after they have been discharged from hospital, as well as the quality of acute services themselves.

CHAPTER



The health care needs of homeless people

Defining homelessness

There is little consensus as to a definition of homelessness – and, indeed, for those who are without a home there are many different ways of experiencing homelessness. Yet how it is defined has important implications for service provision both in terms of identifying the extent of need and in examining appropriate responses.

Watson and Austerberry (1986) have suggested that it is useful to look at the question in terms of a continuum, with sleeping rough at one end and outright home ownership at the other. In other words, "homelessness" is not simply about lack of immediate shelter, but involves questions of security, privacy and access to basic amenities such as cooking and washing facilities. The social and emotional dimensions of having a "home" are largely subjective, which partly explains the lack of an agreed definition. Nevertheless, an understanding of these dimensions is crucial if services to homeless people are to be provided in a way that is both appropriate and acceptable to them.

Although the 1985 Housing Act does provide a useful definition of homelessness, it does not match up with the numbers of people officially registered or *accepted* as homeless by local authorities. The Act recognises people living in temporary accommodation and people without security of tenure, but figures held by local authorities are limited to people accepted as being in priority need only. In order to be accepted, those presenting to local housing departments must fulfil each of the following criteria: local connection to the borough, "unintentional" homelessness, and in priority need – that is, people with dependent children, elderly people and those who are vulnerable through physical or mental ill health. However, "vulnerability" may be interpreted in different ways by individual authorities and methods of assessment vary between boroughs. This means that:

Single people, childless couples and couples with non-dependent children are excluded from the current legal framework of the Homelessness Act. They can usually only gain admittance to this framework by being deemed vulnerable, and this involves the exercise of discretionary power. ... The current principal role of the homelessness legislation is characterised by the phrase "safety net", but in practice it is only a safety net for some.

(Faculty of Public Health Medicine, 1991, p.13)

The fact that single homeless people are not represented in official statistics makes it extremely difficult to quantify the extent of the issue. A large percentage of the homeless population is not visible, and this is particularly true of those with mental health problems. However a survey carried out

in April 1989 by Surrey University (Moore, Canter et al., 1989) suggested there are as many as 75,000 homeless people in London. This compares with estimates from a survey (London Research Centre, 1989) which identified 74,000 homeless people in London.

For the purposes of this research our working definition of homelessness will be based on the idea of a continuum of minimum standards of accommodation. Broadly speaking, single homeless people can be said to share a "lack of a right of access to their own secure and minimally adequate housing space" (Faculty of Public Health Medicine, 1991). In terms of evaluating access to health care this has been broken down into four simple accommodation groups:

- people sleeping rough/in temporary squats (i.e. derelict buildings without services);
- people staying in emergency nightshelters and hostels/long-stay hostels;
- people who are temporarily placed in bed and breakfast/hotel/ shortlife accommodation;
- "hidden homeless people": those staying with friends or relatives/occupiers of squats with basic services.

While people sleeping rough represent the most obvious aspect of homelessness, it would seem that many more homeless people in London are in fact staying in squats, bed and breakfast accommodation, hostels or with friends and relatives rather than on the streets. It should also be recognised that individuals often do not fit in to any one category, but move between the different types of homelessness.

The homeless population

There are a number of factors which influence the way in which individuals experience homelessness and their need of, and access to, health care services. The timescale for this research, however, has meant relying on existing information from established agencies. This has meant that the results are biased towards the needs of the visible homeless, namely those living on the streets and in hostels. Below we attempt to show that this aspect of homelessness is only the tip of an iceberg and one which largely excludes homeless women and those from black and ethnic minority communities. The conclusion to be drawn from this is clear. The needs of the street homeless are comparatively well documented and should be acted on without delay; research activity must concentrate on the needs of the hidden homeless so that a programme of action can be developed and implemented at the earliest opportunity.

Hidden homelessness

The common preconception of homeless people is that they are mainly white men. It is important to note that this is directly related to their level of visibility: the existence of direct and indirect discrimination within society not only places women and black people at great risk of becoming homeless, but also means that their needs are likely to remain

hidden. The reality is that the homeless population is as diverse as the population as a whole. Although there appears to be a growing number of people from black and ethnic minority communities living on the streets (as observed through the street work undertaken by the Simon Community) the pattern of homelessness in these groups tends to be more localised "hidden" forms of homelessness in areas of high ethnic compositions:

Much of the homelessness among young black people is hidden, and so society as a whole neither sees it or treats it as important. It is hidden because of its nature, it is not street homelessness. The reasons for this are largely cultural. Of the six and a half thousand currently on UJIMA's waiting list, 99.8 per cent are homeless but actually staying in temporary arrangements with families, friends or renting sub-standard, overcrowded accommodation in the private sector. In many cases they are suffering from racial harassment or from some form of victimisation both from landlords and other residents. . . . This survey showed that 96.3 per cent are living in situations with families and friends which can only be described as precarious.

(UJIMA, 1991, p.5)

There is evidence to show that black and minority ethnic tenants are far more likely to be living in overcrowded and substandard accommodation than white people and that they are three or four times more likely to become homeless (Brown, 1984; London Housing Inquiry, 1988). Fear of racial attack and of police harassment deter black people from living on the streets and even in hostels they are at risk of racial abuse from white residents. These factors inevitably reinforce the hidden nature of black homelessness.

Concern has been expressed about the "relatively high representation of young African-Caribbean men who were homeless on discharge from psychiatric care" (Kay and Legg, 1986). As reported by the Forward Project (1989):

Of the agencies I spoke to, a number of people commented on the existence of a specific sub-group of homeless young black men who were revolving around the hospital door with no adequate preventative provision.

There is also a huge area of need among different refugee communities in London. Refugees who arrive in the country as single people have no statutory right to housing unless they are in priority need for health reasons. They have multiple problems in getting access to services. There is generally a language barrier and they often have no knowledge of what their rights are. Refugees are often living in overcrowded and very poor housing, they find it hard to get registered with a GP and have very poor access to a range of health services.

Homelessness amongst women is also largely hidden, reflecting both the fact that there are far fewer hostel spaces in London for women and the dangers inherent in sleeping rough. For women on the street there is always the threat of physical or sexual assault, and black women are further vulnerable to racial attack.

The extent of hidden homelessness is by its very nature impossible

to quantify, yet research from Social Trends (1989) suggests that the "unwanted guest" is one of the commonest forms of homelessness. As UJIMA has stated, this situation is often precarious: in many cases the accommodation may already be overcrowded, so that the "guest" has to share a room, perhaps with children of the opposite sex. The lack of privacy for all involved will place considerable strain on relationships within the household. Threshold Housing Advice Centre, based in the London boroughs of Wandsworth and Hammersmith, highlighted this issue in their Annual Report, 1990. As this report shows, hidden homeless can be devastating:

The picture we have built up, when doing this research, of the problem facing hidden homeless people is a depressing one. Most of the people had been homeless for between three months and a year. The majority (75 per cent) in this time had not even a bedroom to themselves. Their support networks of friends or relatives, and especially the people they were staying with, were under considerable pressure; their health was affected, not surprisingly when at least half of the people we interviewed were eating mainly take away-food as their staple diet. (p.9)

Homelessness: a public health issue

In 1989 public health reports from both the North East and North West Thames RHAs drew attention to the vulnerability of homeless people in terms of their ability to maintain good health and to access basic health services. These suggest that "The housing crisis in this country over the last decade is a major public health issue ..." (St George, 1989).

The significant reduction in low-cost social housing over the last decade and an increase in the number of single person households are two major factors which have contributed to the rise in homelessness. However, the fact that certain sections of society are more vulnerable to becoming homeless shows that wider social and economic policies and considerations must be taken into account when looking at this issue.

Discrimination

There is clearly a close interrelationship between poverty, poor housing and homelessness. A low income makes gaining access to secure, independent accommodation difficult; being homeless and the irregular lifestyle this imposes is an obstacle to gaining employment. Evidence of low average earnings for women; reduced income support for people under twenty-five years; and higher levels of unemployment in black communities, for example, makes these groups more vulnerable to becoming homeless. As Threshold has stated:

The difficulties the hidden homeless face in trying to find somewhere to live are enormous. Not only are the majority of them women (55–60 per cent), but they are from the ethnic minorities (60–80 per cent) and are young (60–80 per cent are under 26): people who face discrimination against them in society generally.

(Threshold Annual Report, 1990, p.9)

Threshold shows that although over forty per cent of those interviewed were working, over a third of these earned less than half the average wage (for a man on adult rates of pay). Although almost all were prepared to pay at least one third of their wages on accommodation, "in reality that amounted to under 50 per week". Over half of the interview sample said that their living situation affected their ability to perform their job or studies.

There is also evidence that lesbians and gay men are increasingly faced with homelessness as a direct result of discrimination, hostility and often violence from parents and others. A survey of 4,000 callers to the London Gay Switchboard found that "one in four callers saw their immediate housing problem as being directly related to other people's negative reactions to their sexuality" (Young Homelessness Group, 1990). Not only does housing policy and provision fail to recognise the needs of the lesbian and gay community, but recent legislation such as section 28 of the Local Government Act and Clause 25 of the Criminal Justice Bill has fuelled a climate of hostility and prejudice.

HIV and AIDS

HIV and AIDs are a reality for many homeless people. Society has responded to HIV and AIDs with prejudice and discrimination. As a direct result of this many people who have contracted the infection have lost their homes, their jobs and sometimes even lost contact with their friends and family. Their health is then even more vulnerable due to their homelessness, employment status and resulting isolation. It should also be recognised that people living on the streets may turn to drugs or to selling sex as a means of survival. Access to health services and to information is particularly difficult for people who are homeless and have HIV or AIDS. They fear being stigmatised on both counts and if they are drug users or working as prostitutes there is a fear of criminalisation when seeking help.

Benefits

Young people who are homeless may find it impossible to obtain an adequate income. Not only are they discriminated against within the labour market – and even for those in work their lack of experience means lower wages – but recent changes to Social Security benefits mean that people under twenty-five are now assumed to be living with their parents and therefore only eligible for a reduced level of income support. Yet research from both the Young Homeless Group (1990) and Shelter (Diblin, 1991) has shown that for the majority of these young people becoming homeless has been a last resort. A significant number have been homeless since leaving care (forty-one per cent according to a 1979 Centrepoint survey); others have left home to escape from physical or sexual abuse. For them "homelessness is a matter of survival".

It is difficult for people with no fixed address to obtain benefits and this may be compounded by requirements for identification needed to make a claim. Problems in registering with a GP will also affect those

unable to work through ill health. They may be eligible for a higher rate of sickness benefit, but without a certificate from a doctor they are unable to claim even the basic rate. Without any money at all, people have to rely on handouts, begging, petty theft, prostitution or other criminalised activities.

The effect on health

Over the last decade the links between poverty, poor housing and health have been well documented. In 1980 the Black Report demonstrated the existence of wide inequalities in health and that those people most in need of health care have poorest access to services. Since then other studies have not only confirmed these findings but have suggested that the gap is widening (Whitehead, 1987; Jacobson, 1988).

Over half of those interviewed by Threshold said that their living situation had badly affected their health:

I've become incontinent because of the stress.

My eczema has got worse, I smoke more, I've lost weight, I get very tearful.

The room I stay in is damp and I've always got colds now and often lose my voice: at Christmas I developed a secondary chest infection, yet I was always healthy before.

Stress and depression were common symptoms, often compounded by social isolation and the strain their situation imposed on their relationships with friends and relatives; seventy-five per cent said their sleeping patterns had changed for the worse and twenty per cent that they had lost weight.

Homeless people who are refugees may well have escaped from situations where their physical and mental health have been at risk. Conditions in refugee camps are often desperate: infectious diseases and disease associated with poor nutrition may be of epidemic proportions. The persecution they suffered which led to their becoming refugees, which may include torture and/or witnessing the violent deaths of members of their families means that they will also experience high levels of stress. The problems of being homeless in this country will only serve to reduce refugees' health status still further.

In particular these stresses are likely to lead to, or exacerbate, mental health problems. It is clear that there is a need for mental health services which are sensitive to the needs of refugees. There is a danger both of people being misdiagnosed as mentally ill from a lack of understanding of their past experience, and of them missing out on services altogether.

Evidence from a survey of young homeless people sleeping rough has shown that begging and living on the streets results in malnourishment and ill health. Moreover, more than one-third of those included in this survey reported depression and two attempted suicide over a four-week period. Over a third reported getting drunk on at least one occasion to relieve their depression (Young Homelessness Group, 1990).

It is also the case that because the reasons that many young people

are homeless are often related to distressing circumstances in their lives, they may be more likely to be vulnerable to mental ill health. Yet many are wary of statutory services. The mental health worker at London Connection, an organisation working with sixteen to twenty-five year olds, remarked on how aware young people are of the stigma around mental ill health and their anxiety to avoid psychiatric services for this reason.

The homeless population with mental health problems

It is a popular misconception that the closure of long-stay psychiatric institutions has resulted in a vast increase in the number of homeless people with mental health problems. In fact the evidence that is available suggests that it is acute mental health services which are failing to respond to the needs of single homeless people. Therefore particular attention has been paid in this section to the needs of homeless people with mental health problems.

People who are very disturbed and sleeping rough tend not to congregate with other homeless people but to lead a more isolated life. They also escape the attention of people documenting the experiences of homeless people because they are not willing, or able, to engage in conversation about their lifestyle.

The large hostels and resettlement units for homeless men that still exist in London are often described as having a similar population as the long-stay wards of a large psychiatric hospital. The Guy's Hospital Psychiatric Team for Single Homeless People (PTSHP) worked with residents of four large hostels in Lambeth, Lewisham and North Southwark between 1987 and 1990 and "was overwhelmed by both the scale and the severity of the psychiatric need among the men in the hostels". The team worked with clients referred to them by hostel staff. They worked with ninety-five men during the period; of these, only fifteen had never previously been admitted to a psychiatric unit.

Other studies of residents in direct access hostels and resettlement units have come up with similar findings (Marshall, 1990; O'Neill, 1990). Moreover, all these studies have shown that these groups are by and large escaping the attention of the health service and were very often not registered with GPs.

Bed and breakfast accommodation

Single homeless people who have mental health problems may be eligible for housing under the Homeless Persons Act, if they are deemed vulnerable because of mental illness and therefore in priority need. People who are mentally ill form four per cent of the total of those accepted by local authorities as homeless. In 1990 there was a seventy-five per cent increase in the number accepted as homeless for mental health reasons in London (Diblin, 1991).

These figures indicate the number of those who are *accepted* as being in priority need. As Kay and Legg (1986) note in their research, it is very difficult to get any statistics on the number of single people *applying* to local authorities on the grounds of being vulnerable for reasons of mental ill health.

Given the dearth of statistics on need, there is no way of knowing how many allocations should be made a year to mentally ill applicants. All we know is that there was unanimous agreement from everyone we talked to that there was insufficient council housing allocations to meet these needs.

Most single people who do get allocated housing by local authorities in London get places, at least temporarily, in bed and breakfast accommodation. This type of accommodation is clearly unsuitable for people with mental health difficulties.

People are often sent to boroughs where they have no contacts. No support is offered, it is isolating and, due to its temporary nature, they are unable to make links in the community. They have very little space so they are unable to invite friends and visitors.

In every way it is an alienating and unsuitable environment and yet it is where many people with mental health problems are forced to live for long periods. Social workers and advice agencies find themselves having no alternative to sending someone along to the Homeless Persons' Unit because they cannot find more appropriate accommodation for those in need of a high level of support.

The ultimate irony is that the people needing the most support we end up placing in bed and breakfast because we can't find a hostel that feels it can offer the level of support they need.

(Worker at Alone in London)

Again this underlines a recurring theme within this section: that acute services cannot be seen in isolation from preventative and community health and social services and that people's acute health needs cannot be seen in isolation from the circumstances of their lives.

Access to services

It is clear that the effects of poverty and homelessness are detrimental to health status. Yet it is important to understand that the lifestyle imposed by being homeless means that issues of survival will inevitably have a higher priority than health and health care – for example, finding a home, or even somewhere to stay the night, gaining some form of income and food to eat.

These issues affect all homeless people, both visible and hidden. Although much of this section of the working paper will be looking at those living on the streets, it must be emphasised that this is only the tip of the iceberg. Health authorities and those providing services must therefore recognise that the homeless population is not a homogenous group with identical needs: this means that the dimension of homelessness has to be considered in all aspects of service planning and provision. In particular the hidden needs of women and black people can only be addressed in the context of ensuring that these groups of users have equal access to quality health care. At present they are doubly discriminated against by virtue of their homeless status and by institutional and individual racism and sexism, both within society and with respect to the delivery of health services.

CHAPTER



The homeless care package

The following account aims to present an overview of the existing "care package" for single homeless people. It will look at homeless peoples' experiences of preventive and primary care, admission to hospital, their experience of being in hospital, and, finally, discharge and aftercare in the community. In so doing, an attempt is made to evaluate the *quality* of services received by this user group on the basis of Maxwell's criteria for evaluating services.

Mainstream primary care services

GP services are the main gateway to acute services. Access to the acute sector is largely based around GP referrals – both at accident and emergency level, and as a route to planned (elective) admission. Without any form of preventive care, early diagnosis and intervention, the most likely route of access to the acute sector, is through self-referral or emergency admission.

Rates of GP registration

It is extremely difficult to ascertain accurate levels of GP registration for the range of different people within this continuum definition of homelessness. Different types of registration confound the problem further. Often people are themselves unsure whether they are registered as permanent or temporary patients.

People who are sleeping rough and have no fixed address have the greatest difficulties getting registered. A worker at a day centre for homeless people in Haringey recently wrote to twenty GPs in her area asking if they would register her clients. Not one even bothered to acknowledge her letter. Bloomsbury CHC and the Medical Campaign Project (1989) have shown that this experience is not unique, and agencies have also received hostile replies to enquiries, such as "It's not my job to look after all the waifs and strays".

Evidence as to the extent of registration amongst homeless people in different accommodation groups is partially illustrated in the Policy Studies Institute (PSI) (Williams and Allen, 1989) study of two specialist health projects set up in Camden and Islington, and City and East London Family Practitioner Committees (FPCs) (see Table 10.1).

It should be noted that this study defines registration as with "a GP in London or elsewhere". It seems incredible that this important piece of research has failed to distinguish between local registration and registration with a doctor outside London. The Camden and Islington FPC subsequently produced data paying special attention to the

Table 10.1
Accommodation status of homeless people who have registered with a GP in Camden, Islington and City and East London FPCs

		Accommodation status									
	Total	A	В	С	D	E	F	G	Н		
GP reg. (per c	ent)								•		
Yes	60	27	33	75	70	72	50	85	70		
No	40	73	67	25	30	28	50	15	30		
Base: all	(190)	(52)	(9)	(4)	(27)	(18)	(8)	(47)	(23)		
Key to table: A Sleeping rough/skippering B Squat C Hostel/night shelter D Short-stay hotel		E Long-stay hostel F Hotel/B&B G Own H Other									

Table 10.2 Location of registration with a GP of homeless people in Camden and Islington

Centre	Patients	Reg.	London	Outside	Unknown	
1	322	105	55 (17%)	34 (10.5%)	16	(0.5%)
2	193	78	41 (21%)	24 (12.4%)	13	(0.6%)
3	61	19	9 (14.7%)	6 (10%)	4	(0.65%)
TOTAL	576	202 (35%)	105 (18%)	64 (11%)	33	(0.6%)

location of registrations (see Table 10.2). Data is presented for people seen at three centres.

Further caution must be added to the interpretation of these figures. As noted previously, they represent only those people who make use of specialist services. There is further evidence to suggest that registration amongst rough sleepers is much lower. This was indicated by the Simon Community study (Ansell, 1989), which discovered that as many as sixty-four per cent of the people they interviewed were not registered with a GP.

Barriers to access and quality in care

Temporary registration

People without a fixed address are more likely to be registered as temporary patients: no medical card is issued and medical records are not available. The system lacks continuity of care, often leaving patients with a lack of information about their medical problem and treatment. They may see a succession of different health professionals attending to their more immediate needs. Underlying conditions are likely to go undiagnosed, or simply ignored.

GPs should be encouraged to register homeless people on a permanent basis whenever possible (and certainly if they have been seeing someone for longer than the three-month period of temporary registration) as only in this way can homeless people have the same right of access to a comprehensive range of services as anyone else. Existing models of user-held records, such as those used in neonatal clinics, are useful examples of attempts to establish continuity of care between health professionals. Similar models should be developed for people who are homeless and who have not been able to register with a doctor on a permanent basis.

The possibilities for elective or planned admission to acute services are dependent on a person's level of contact with primary care or accident and emergency services. There is no evidence to suggest that GPs are less likely to refer homeless patients for elective admission than any other patient. Nevertheless, decisions about "when to treat and when not to treat" are increasingly influenced by the availability of resources and thresholds for admission.

The decision to refer may be based on doctors' perceptions about the patient's motivation or likely compliance with treatment. Decisions can be made on brief, even cursory contact with the patient; medical notes are not available, and there is little possibility for contact with next-of-kin. Inequalities often stem from a lack of knowledge about a patient, or lack of awareness about what support services are, or are not, available. It should also be pointed out that people with no permanent address can be extremely difficult to contact. Admission is likely therefore to be postponed or cancelled.

Need for a fixed address

If a person has no address at all, then administrative barriers (actual and perceived), will influence the outcome. There is no standard practice within family health service authorities (FHSAs) for registering people without a fixed address. Nevertheless, practices working within a defined geographical "patch" require evidence in the form of an address to prove that the person lives in the area. This makes it more difficult for people who are sleeping rough, despite the fact that they may have been sleeping in the area for long periods of time.

Mobility or change of contact address is a factor likely to affect whether a person is registered locally. It is not possible to generalise about the mobility of different groups within the continuum, only that it is likely to affect people at all levels. Threshold Housing Centre (1990) reports that it is common for their users to be frequently changing their contact address as they move from friend to friend. It should be remembered that mobility is often enforced, either through housing transfers between and across boroughs or in the case of "unwelcome guests" - the necessity to move on. Mobility creates disorientation and is a drain on time and energy. Each move involves more bureaucracy and administration for housing benefit, education, etc. Unless a health problem is immediate, registration with a GP is likely therefore to take on low priority. As Duffell (1989) has argued, the current system of accessing health care through GPs is both bureaucratic and off-putting and marginalises many groups, including homeless people. There is a need to review these services and to identify ways of overcoming the barriers to access which discriminate against these groups.

The need for a fixed address is clearly a form of institutionalised

discrimination which is perpetuated by the inflexibility of General Practices and their governing FHSAs. Camden and Islington FHSA have attempted to overcome this by allowing people to give a contact address, such as a day centre, when registering. Lambeth, Lewisham and North Southwark FHSA have taken this flexibility a step further by allowing people to use the FHSAs own address as a point of contact. These are examples of good practice which could be followed by other authorities. However, it must be said that such policies are meaningless unless they are well publicised both to users and to GPs and their staff.

Prejudice

Prejudice and discrimination depend a great deal on a person's appearance, or "social acceptability" in addition to their homeless status. Homeless people are likely to experience prejudice not only from doctors, but also from nurses and receptionists. As the first point of contact, an unsympathetic response from a receptionist can act as a deterrent without a person seeing a health professional. This problem is a familiar one to people working in homeless agencies:

It is important to note that it is not just the prejudice of GPs themselves that put homeless people off using mainstream doctors, but also the attitudes of nurses, receptionists and other members of the public. Indeed, an often given reason for not registering a homeless person is that their presence in the waiting room will drive other patients away. Stereotyped attitudes — a perception that all rough sleepers are always drunk and belligerent, or loused up, or wanting the doctor to prescribe drugs they will subsequently abuse — appear to lie at the root of much of this prejudice. These attitudes also appear to be a factor in the frequently cursory and degrading treatment that homeless people receive from some GPs once they have succeeded in registering.

(Ansell, 1989)

The training scheme for GPs should cover issues relating to the health needs of homeless people and so aim to break down traditional stereotypes of homeless people and increase awareness of the problems they face. All London GPs should undertake training in this area. FHSAs should favour applicants who have undertaken such training and who have a sympathetic attitude towards homelessness when appointing GPs to a new or vacant practice. FHSAs should also establish training for practice staff, including receptionists.

A hotel, hostel or nightshelter address is in itself no guarantee for registration. Often, the stigma it is associated with can be a positive disadvantage to someone trying to register. Variations exist between the local profiles of different establishments, and so people may be perceived according to the "type of person" supposed to be living there. Some hostels are even systematically avoided by GPs.

Support and advocacy

Priority attached to health care within hostel organisations varies also. At one end of the scale there are on-site clinical sessions held by salaried medical staff. At reception centres this goes as far as compulsory medical check-ups on admission. This interventionist approach contrasts with

non-interventionist styles of management in many short-stay hostels and night-shelters. Hostel workers themselves often have low expectations of health services and see their role primarily in providing accommodation. There is a tendency for hostels to use one local practice which is prepared to take on all residents. This does not ensure quality of care as it offers little choice and can lead to difficulties changing GP.

The possibility for support and advocacy within hostels is dependent largely on levels, and deployment, of staff. At the Arlington House a Health Care Co-ordinator is in post. She acts as a health advocate and provides on-site nursing treatment. All 380 men living at the hostel are registered with a sympathetic local practice. This arrangement is the result of many hours attempting to forge links with local GP services. Other salaried health workers based in hostels and reception centres have commented on the time-consuming and often demoralising nature of liaison work. Although salaried health workers have a significant impact on clients' access to local services, comments from them suggest that contact with services outside these locally forged links tend to be more problematic. Also these links tend to be informal, as one hostel nurse said:

It has taken us a long time, but we do have fairly good links with local health workers, but outside of that we have real difficulties. It is also a problem that these links are all based on personal good relationships with individuals — when they go we have to start the process all over again with someone new.

It is clear that homeless people have problems accessing primary care services and particularly in registering with GPs. A report to Brent and Harrow FHSA (Mahida, 1990) recommended that the FHSA should have a named person responsible for issues relating to homelessness who would provide a point of contact within the authority for individuals and agencies. This study would endorse this recommendation and suggest that this person should be responsible for liaising with agencies working directly with homeless people to ensure that their clients are able to exercise their right to primary care.

Care in the community

Home visits

For people sleeping rough, home visits are a contradiction in terms. For single homeless people living in temporary accommodation, "care in the community" is also extremely meagre. Health visitors and community midwives have a statutory duty to visit families and new-born children placed in an area. The service relies on effective communication between sectors and different boroughs. Front-line health workers complain that these links are extremely weak. Other problems they have described include: "professional isolation, lack of staff, inadequate record keeping, the difficulty of identifying households, the mobility of the population and the multiplicity of problems encountered" (Faculty of Public Health Medicine, 1991).

Access to community nursing staff is usually via a referral from a

GP. Without a GP, single homeless people can therefore be denied access to these services as well. There is little possibility for community health workers to undertake proactive outreach work in hostels and other homeless centres. Lack of resources and low staffing levels effectively leave many "vulnerable" single homeless people without any form of nursing care or support. As a worker in a night shelter said:

District nursing staff in our area provide a high level of care to our residents and we have developed a good working relationship with them. Unfortunately this work is not valued by their managers who have decided to stop this service in order to make financial savings.

Community health services should be provided at a sufficient level to meet the needs of homeless people within their patch and to ensure that these users do not "fall through the net".

Social service domiciliary visits tend also to be out of reach. The extent and range of these services vary from borough to borough and, as Part 2: "Acute care for older people" makes clear, social service cutbacks make it increasingly difficult even for the housed population to obtain services appropriate to need.

Maintaining links

Enforced mobility amongst people placed by housing authorities create difficulties for users in maintaining links with services once they have been established. People may be moved several times over a short period, appointment cards may not reach the client in time, hotel managers may not return mail to the Homeless Persons Unit (HPU), or client details could get lost in the HPU system. The help that single homeless people receive relies largely on self-referral. (Hospital referrals can also be problematic – these will be discussed later in relation to aftercare services.) It is therefore vital that systems are established to ensure the regular flow of information between agencies. This would be further enhanced if formal links are also established between named persons within each authority who could also be a point of contact should problems arise.

Specialist primary health facilities for single homeless people

Supply and demand

Although there are isolated examples of good practice within mainstream GP services, attitudes amongst GPs on the whole remain unchanged. If anything, the insecurity over new NHS changes increases their resistance to registering homeless people. Meanwhile, low levels of GP provision in central London make it increasingly difficult even for the housed population to register permanently with a GP. Although there have emerged some individual practices known to provide a sympathetic service, single homeless people often have reasonable cause to fear rejection. These difficulties are more pronounced amongst longer-term hostel-dwellers and rough sleepers.

Often people resort to using casualty departments for their

primary care needs: this is discussed later. The failure of mainstream primary care to provide equal access and sympathetic treatment has led to the development of specialist services for homeless people. These tend to be targeted at existing homeless agencies, hostels, nightshelters, day centres or statutory-run reception centres and hence at the needs of the street homeless population. To this group they offer a number of advantages. They provide a service which is flexible, i.e. does not have rigid appointment systems, which treats homeless people with respect and which understands their needs and circumstances.

However, it is also the case that these services can serve to further marginalise people from mainstream services and their ability to provide continuity of care or choice is often very limited. Resources are generally inadequate for providing much needed continuity in this type of services. Input from nurse practitioners is often the most continuous element from the users' point of view. However, this raises the problem of referral: for example, a nurse may wish to refer someone for secondary or tertiary care, but this will not be accepted unless it has been authorised by a doctor. This is clearly an additional barrier between primary care services, where many non-medical practitioners are used to working autonomously and to having considerable responsibility towards those in their care, and the acute sector. There is clearly a need to review current procedures to enable community health workers to make appropriate referrals to other services such as acute medical specialties.

Quality of care

The "success" of specialist projects relates directly to the intransigence of mainstream GPs to take responsibility for the care of homeless people. Their success should also been seen in the perceived *quality* of service they provide. Many people are prepared to travel long distances just to see a doctor or nurse who will provide sympathetic treatment. The Simon Community study (Ansell, 1989) concludes that:

The major attraction of these services was that they were perceived as being for homeless people and as far more sensitive to the needs and feelings of homeless people. Workers within these services are seen as understanding homelessness and as being prepared to listen to what the patient has to say, rather than simply brushing him or her aside as simply drunk (and therefore by implication, not ill or hurt). Other advantages are flexibility and accessibility; for example, being able to see a doctor as part of one's daily routine and not having to make an appointment.

Towards integration

For the majority of single homeless people specialist forms of service provision are clearly inappropriate. Their specialist or "segregated" status makes them off-putting to people who do not identify with, or are outside, the established homeless "circuit". Where they work best is in their ability to provide an outreach service which can help link people into the services they need, to offer support and advice about local health services to homeless agencies, and to inform mainstream health workers about the needs of homeless people. Much can be

learned from the experience of specialist services which have developed ways of working which are acceptable to homeless people and responsive to their needs. These ways of working should be replicated by mainstream services.

Ambulance services

Ambulance services are often reluctant to attend to people who have not been referred by a GP. Many homeless people reported hostility from ambulance staff: "They treat you like animals, they're always gloved and masked before they touch anyone". Almost all the hostel and day centre workers contacted for this study supported this view, giving accounts of negative attitudes from ambulance staff towards their clients as well as a reluctance to attend when they gave the address of the hostel or centre. The following quotation was typical:

It was obvious to us that John had had a stroke, I mean, he had never been a drinker, but that was what the ambulance staff assumed – it was obvious that to them he was "just another drunken dosser wasting their time". They hadn't wanted to attend at all when we gave them the address of the Centre and when they did come (forty minutes later) they were rude to everyone, including the staff.

It is clear that the difficulties homeless people have in registering with a GP not only denies them access to twenty-four hour care, but also is an obstacle to prompt attention from the emergency services. Again this emphasises the need to break down ingrained stereotypes of homelessness and to encourage a more sensitive approach from all front-line health workers.

Primary care in accident and emergency departments

Poor access to primary care services means that homeless people have little choice than to use accident and emergency departments for their health care needs. However, it is apparent that their use of accident and emergency as a substitute for GP services is not welcomed by accident and emergency staff, who see them first and foremost as "inappropriate attenders". This, together with negative stereotypes which staff may hold and a lack of understanding of their circumstances, means that single homeless people often receive a poor quality service which does not meet their needs. Accident and emergency departments may not be the most appropriate place for them to seek primary care, but in the absence of alternative provision it is the only place they can go. This should be recognised by service providers.

Waiting times

The triage process ensures that "inappropriate attenders", that is those who do not require "the sophisticated technology associated with a modern hospital" (Farmer and Chambers, 1982), will have the longest waiting times. These can be as long as eight or nine hours. To homeless people it can be felt as direct prejudice against their homeless status.

I was in casualty for seven hours, I had a cut on my arm. I've never had a tetanus injection in my life, but because I'd been drinking they told me to fuck off.

Casualty were useless. They only seemed to be concerned about whether you're drunk or not.

I was stupidly fobbed off by doctors at A&E, they were very brusque and belittling. Doctors should be more intelligent.

They should tell people how to register and they should provide baths. Hygiene comes with health.

Not surprisingly, there is no firm evidence to support the use of punitively long waiting times as a deterrent to homeless attenders. However, it should be pointed out that the methods used to "reeducate" users – such as notices placed in entrances or in waiting areas, verbal pressure from reception staff or triage nurses – actively encouraging patients to consult their GP or to seek registration, may be a strong enough deterrent for some users.

There seem to be many layers of discrimination that operate in accident and emergency departments. Very poor and unsympathetic treatment seemed to be common experiences of people presenting with a mental health problem. They felt they were doubly discriminated against for being homeless as well and were often treated with suspicion and irritation. The worst reports received were from agencies working with young homeless people and those working with black people with mental health problems. These groups seem to have a particularly raw deal. The Forward Project described the experience of a young black man who had tried to get himself admitted at several different hospitals and who attempted suicide after being consistently turned away.

Many homeless people have become accustomed to rejections from public services, and may perceive this kind of pressure as a refusal. Many people are unaware that they have the right to insist on being seen by a doctor and therefore are likely to leave the department without waiting. Quotes from homeless people themselves suggest that some believe a GP referral to the accident and emergency department is essential.

Treatment

Even getting seen does not guarantee that appropriate treatment and advice will be given:

Another resident collapsed and was seen at casualty and sent back to the hostel as being alright. Later that evening he developed diarrhoea, shurred speech and lost all co-ordination and lost sensation in one arm. He was seen the following day and was deemed alright. Five days later he collapsed again and was admitted to hospital. Eight days after his initial collapse he died.

(Medical Campaign Project and Bloomsbury CHC, 1989)

Bob had been attending the day centre for some months. On one occasion in December he was sleeping out again, despite the freezing cold and although he had been drinking he was sober when he got to us. With no warning he had a major epileptic fit which lasted several minutes, and was unconscious for a short time afterwards. As he fell he cut his face quite

badly. An ambulance was called and took him to hospital. He was back with us within the hour. Although his cut had been dressed he had not been examined and the cause of the fit had not been investigated at all.

(Nurse in day centre)

A hostel nurse described the case of one resident who came to her with what was obviously a fractured ankle – his foot was clearly pointing in the wrong direction. It transpired that he had walked the two miles to the hospital on his injured ankle to keep an appointment at the accident and emergency department for a chest X-ray previously arranged by his GP. He asked the radiographer if they could also X-ray his ankle, but he was told he would have to get a letter from his GP. He therefore walked the two miles back to the hostel to see the nurse there. A letter of complaint was sent to the radiology department:

Whoever dealt with him must clearly have seen that he was barely able to walk to, or from, the X-ray room. Had they considered this fact and thus given a brief glance down to his foot, they would have seen exactly what I did later that day. A letter from a GP does not seem to me to be reasonable advice to have given under the circumstances. It would have been more useful, and certainly less painful, to have told him to go downstairs and book into A&E.

Mr Roberts is not a very intelligent man; nor is he able to manage verbal communication very well (he did not speak until he was twelve years of age); nor has he any idea how to use the health service except to do what he is told — hence his seeing me at 4pm to get a GP letter.

Workers in voluntary agencies are so concerned at the hostile reception that homeless people are often subjected to in accident and emergency departments that they accompany them to the department to advocate on their behalf. Many workers told us that a considerable amount of their time was taken up by this and that it is a considerable drain on their limited resources. Meanwhile, service providers are in the habit of assuming homeless people use accident and emergency departments as a form of shelter, or as a way of killing time:

Homeless people are thought to use the A&E department both as an open access primary health care service and as a resting place and a source of confort and attention.

(Crown, 1990)

Alternatively, it can be argued that homeless people who lack GP support should be given priority within the accident and emergency system of triage. Service providers should be prepared to accept that for homeless people time is also of the essence – for example, they may need to find somewhere to stay, that tolerance for long waiting times is often lower and, being homeless, they are very vulnerable.

"Time is of the essence"

The pressure to ensure a fast through-put of patients in order to prevent long waiting times is one of the main priorities of accident and emergency organisation. This factor significantly influences the quality

of primary care received by accident and emergency attenders. People are generally treated only for the condition which prompted their attendance; medical notes are rarely available and underlying illnesses are likely to be left untreated.

Follow-up

At accident and emergency level, the main difficulties relating to quality and continuity of care, arise in the organisation of follow-up and outpatient appointments. Follow-up is usually arranged with a patient's GP through a standard discharge letter format. Interviews with casualty staff showed that unregistered patients are likely to be discharged from the department without any form of discharge letter. Interviews with doctors indicated some variability between the time and trouble taken to write openly-addressed letters. In the absence of medical records, an openly-addressed doctor's letter can be of great use to someone should they present for treatment elsewhere and may also help to secure accommodation. Greater consideration should be given to follow-up treatment.

Usually people are advised to return to the department for followup. It would seem that a great deal depends on individual doctor's initiatives or willingness to work flexibly – that is, according to individual needs. This quote from a casualty officer illustrating flexibility and commitment towards patient follow-up also suggests a certain amount of distrust towards other casualty staff:

Well what I usually do is to get them to come back here to see me. And I'd sort of work out when I'd be on in the following week so they would actually come in when I was there and I'd know what they came in with and what I'd done.

Again there is an ecdotal evidence of homeless people being given poor or inappropriate advice:

Tom had his leg in plaster when he first started using the day centre, but I began to grow concerned when he was still in plaster some weeks later. When I asked Tom about it he said that it had been on for five months, no-one had told him when he should come back. I sent him to the hospital where the plaster was removed, revealing a nasty sore which had developed underneath. A nurse dressed the sore and he was discharged with a supply of dressings. He was told to change the dressing every day and to keep his hands clean when he did so, so as not to infect the wound. Yet they knew he was living on the streets. Inevitably the wound became infected and he had to be admitted. In the end we contacted his sister in Ireland, a nurse, who took him home. She later told us that it took nine months for the wound to heal.

(Day centre worker)

"Contact" addresses may be used by homeless patients, although these are not necessarily asked for at registration. A lack of contact address can frustrate doctors' attempts to provide follow-up treatment. Alternatively, some contact addresses (even a hostel or hotel address) can conceal a person's true homeless identity. People may also give a false

address in order to avoid being labelled. Inevitably, in some cases staff will fail to recognise someone as homeless, and this carries with it the risk of inappropriate care and advice being given. Sensitive questions about the permanence of an address given should be a standard part of the initial patient interview to try to overcome this problem.

Discharge to the street

Homeless people attending accident and emergency departments often present with a range of different medical, social and housing needs. Most accident and emergency departments are simply not geared or equipped to deal with patients' multiple needs. The time factor, low staffing levels and lack of training all tend to militate against the possibility of necessary liaison work. For people without the means to find adequate accommodation, there is obviously a great risk of deteriorating health, and the likelihood of re-attendance or admission.

Although some hospitals have paper policies which state that accident and emergency departments have a responsibility to consider a patient's need for additional support, the realities of accident and emergency organisation do not reflect these ideals. Evidence from interviews with staff indicates that assessment of this kind is extremely ad hoc. If a homeless person's condition does not warrant admission, then discharge from the department effectively means discharge to the street. Patients at accident and emergency departments are regarded as either warranting admission, needing a referral to outpatients, or deemed fit to be discharged. Many of the staff interviewed expressed concern about the frequency with which homeless people are discharged in an unfit condition, but, at the same time, considered that this kind of time-consuming liaison work is incongruous with such a highly pressurised accident and emergency environment.

The problem is more acute at night, when discharge to the street is clearly less acceptable. Referrals for emergency accommodation after ten o'clock at night can be virtually impossible to arrange. At times, patients with nowhere to go may be permitted to sleep in the waiting area overnight. However, this arrangement would seem to vary, depending on weather conditions and which of the senior staff are on duty and willing to "turn a blind eye".

Information resources

It seems highly inappropriate that the availability of essential information about homeless agencies should rely on individual staff initiatives; however, this is often the case. The use of information directories, for example, is discouraged by the accident and emergency culture, where staff are expected to rely on recall or information "at the fingertips". This lack of information creates a great deal of irritation for hostel workers who often complain of inappropriate referrals from hospitals. There is clearly a need for a range of accessible information to be made available to both staff and users – for example, how to register with a GP, the names and addresses of local advice agencies and their opening times, and hostels. Such information should be reviewed regularly to ensure that it is comprehensive, up-to-date and accurate.

Assistance with registration

Usually, accident and emergency departments do not actively assist with GP registration, although one exception is St Mary's which provides handout lists of GPs in the surrounding area. More often a department's formula is simply to advise people to seek out lists at local post offices or libraries. This kind of advice is inappropriate, not only because most post offices do not keep lists, but also because for many people libraries are alien places – moreover, problems with literacy are more widespread than is commonly believed. In some instances homeless people may be referred to a specialist primary care service, but this kind of "pigeon-holing" fails to help people get into mainstream community services. On the contrary, it reinforces current patterns of use amongst people who alternate between specialist providers and different accident and emergency departments.

Accident and emergency departments should provide assistance with registration, but more training is needed for frontline workers who currently have little understanding of how primary and community care services are organised (Green, 1991). In particular staff need to be aware of people's rights in relation to GP services, such as their right to register for immediate necessary treatment at the very least.

Models of care within accident and emergency departments

GP services at accident and emergency departments

One remedy for the problem of inappropriate attenders recommended in the Nuffield Report (1960) was the employment of GPs on a sessional basis to screen and treat primary care attenders on site. This model has come into existence at Kings' College Hospital accident and emergency where local GPs are employed on a sessional basis to work alongside the accident and emergency team. They relieve the department of this workload, and provide a more effective primary care service at accident and emergency. A similar scheme is being introduced by the Royal London hospital.

Another model intended to reduce the primary care workload of casualty officers is the introduction of nurse practitioner schemes. Patients will be seen by the nurse practitioner if their presenting problem does not warrant attention from a casualty officer. The role is also seen as an attempt to come to terms with "self-referred emergencies", and, in so doing, to provide a more comprehensive response to a person's multiple housing and psycho-social needs. This scheme has been introduced by University College Hospital accident and emergency department and part of the training programme for the nurse practitioners has included input from homeless agencies and specialist alcohol and drug dependency services.

A third model is that of a liaison worker employed within accident and emergency to help link people into appropriate mainstream health and social services as well as with voluntary sector agencies who can provide assistance and support to someone leaving the department.

Having GPs, nurse practitioners or liaison workers (or a combination of these) within the department increases the likelihood of

ensuring continuity of care and the provision of appropriate treatment to those users not requiring "sophisticated medical technologies". Many of these schemes are only in their infancy, but their progress should be monitored closely to see how far they will go towards providing future models of good practice.

Social work input at accident and emergency departments

Social Service cut-backs have in recent years left a number of accident and emergency departments without attached social workers. Those without on-site social work input rely on a rota system through which "on-call" hospital social workers can be contacted for emergencies during office hours. Out-of-hours calls are directed to the area team.

It seems that social workers are called in only for "real" emergencies. Accident and emergency staff are aware of the pressures social workers are under, and the amount of time it takes for them to reach the department. "You can never get one when you need one". At St Mary's Hospital, Paddington, there are written guidelines for staff to follow which serve as a basic definition of the social work department's role in emergency cases.

These should be delayed if at all possible until the hospital social work department is open and one of the social workers here can see the patient, but in the case of a real emergency, i.e. a non-accidental injury or sexual abuse to a child, or a mentally ill patient, possibly requiring sectioning under the Mental Health Act etc., staff should know there is a 24-hour social work service available in Westminster.

At other hospitals the "on-call" facility appears to be used very sparingly. If a person appears to have need of social work assistance, he or she may be told to go to the hospital social work department's main office. Here, he or she may receive money for fares, and a list of emergency accommodation. Again, this system is based on self-referral, and relies heavily on the user's own initiatives to "sort themselves out".

Referral for detoxification

Requests for alcohol and drug detoxification at accident and emergency departments are common. However the lack of specialist inpatient facilities, as well as detoxification centres in the community, means that access is extremely limited. The low profile of this specialty within hospital medicine is clearly anomalous to current demand.

The decision to admit someone for alcohol detoxification rests largely on medical criteria, that is, extreme symptoms of withdrawal. The following statement by a casualty officer illustrates the medical criteria for admission, as well as the low priority attached to detoxification (plus his lack of knowledge about facilities that are available).

Well do I do it? Do I refer people to detox? No I don't, I don't personally send people to detox. And that's really my own ... mmm ... I think as an organisation, yes ... I would not usually send someone to our team here for detox, unless they were seriously unwell ... If someone is having fits. But if the person is just having shakes then I wouldn't ... they would have

to be incapable of leaving the department — and there are other facilities for detox ... there are some ... There's a hostel in south London where they can be sent, but most of them claim they can't make it round the corner, never mind to South London. But there's nowhere else that I'm aware of.

Homeless "pathologies"

A special type of institutional discrimination hinges on the medical profession's attitude towards conditions which are classified as being the result of "self-abuse", or "self-neglect". These include alcohol and drug-related problems, habitual overdose, infestation, injury through inebriation or fighting, and long-standing, untreated problems. Perceived levels of poor motivation and compliance with treatment amongst homeless patients would seem to militate against the possibility of staff administering effective treatment. Alcoholics are particularly disadvantaged within medical settings, as doctors often require that they attend sober.

The following quotes from accident and emergency staff show how the "kill or cure" approach decreases the possibility for a positive therapeutic relationship developing. Proving one's "motivation" seems to be the key to this:

going back to the gastritis ... I mean they can if they wanted to for the price of their Tenants Super, they could go into a chemist and buy some antacid. You can explain that drinking causes their problems and that whilst they're drinking it is important to take something to combat the problem...but yes, I would not write out a prescription for them — it's not what the function of the casualty department is ...

You get the feeling that they're probably unreliable, and that could be prejudicial because they might not be. Certainly I've met some that seem like they could be very reliable. However, it is a general feeling that their low self-esteem is conveyed to you and you feel that they will probably not bother to do what you have asked them because they just can't be bothered with looking after themselves. That's the sort of angle I have. ...

One of the main thrusts is "go and get yourself registered" — I think people have a responsibility for their own health, and that means able-bodied people can get themselves down to the local library and then get themselves signed on with a GP ... And I think when people take no responsibility for their own health then, I as a person feel very much more reticent I think, about being as helpful as possible.

A major problem is the fact that there are so few places to refer people to and that many detoxification centres have fairly lengthy waiting lists. A range of different types of provision for people who have problems with alcohol is desperately needed.

Institutionalised discrimination

Like other marginalised groups in society, homeless people experience institutional forms of discrimination within the normal patterns of service delivery. Hospital structures and procedures are generally based on the assumption that patients are registered with a GP and have

adequate accommodation and home support. As this report illustrates, homeless people fall outside the normal "care package", and consequently suffer inequalities in health. Although the Black Report (1980) failed to include unemployed and homeless people in its nomenclature of economic status, there can be little doubt that homeless people suffer greater inequalities in health and access to health care than the lowest occupational groups it identified. Throughout this study there are illustrations of institutionalised forms of discrimination at various stages of hospitalisation.

Direct forms of discrimination

It is often difficult to distinguish clearly between direct and institutionalised forms of discrimination. However, there is some point at which personal attitudes as well as medical stereotyping are the main barriers to access and quality of care. Black people and, indeed, Irish people also suffer from racial stereotyping and are therefore doubly discriminated against if they are also homeless. As one worker in a community centre for Irish people told us: "Health professionals assume that if you're Irish you must also be an alcoholic; this means that our health needs are not taken seriously".

It is clear from the Black Report that the social distance between professional classes and people of low economic status affects the treatment people receive. This is illustrated by the following quotations from doctors:

I'm less sympathetic towards the druggies and the alcos because I feel that they don't take any responsibility for their lives.

But there are different kinds – there's the older bum, the traditional bum who will have perhaps five overcoats and three jerseys and a can of lager and nicotine stained hands, and then there's the young smartly dressed adidas – sporting down and out.

Service providers often are unconscious of the fact that for a lot of people, entering a public setting (for example a GP surgery or accident and emergency department) can bring with it a great deal of insecurity. The motivation this sometimes requires indicates *need*. The powerful effect of past experiences cannot be underestimated. An individual's fears are augmented also by experiences related to them on the homeless grapevine.

Getting admitted to hospital

Accident and emergency thresholds for admission

Official descriptions of homelessness and its implications for acute sector delivery emphasise that for homeless people thresholds for admission are lower because of the risks attached to discharge. Indeed many conditions homeless people present would not otherwise warrant admission if they were not "at risk". Doctors may be more likely to admit a homeless person if they are unsure about their initial diagnosis, or are waiting for results of tests.

However, in light of previous illustrations of discrimination, and the difficulties homeless people face gaining initial *access* to services, the *actual* thresholds for admission is brought into question. Again, the problem of prioritising resources and the decision of "when to treat and when not to treat" is raised. In addition to the obstacles homeless people already face, the actual shrinkage of acute hospital beds in London has led to the "admissions nightmare" (as described by frontline doctors negotiating beds for emergency patients).

Case histories of homeless people being discharged inappropriately from accident and emergency departments provide further evidence of discrimination in acute hospital provision. Like elderly people, the homeless are perceived as "bed-blockers". There is no firm evidence to suggest that this affects the threshold for admission, but it would seem that the current sense of crisis amongst service providers, partly due to the closure of hospital beds, makes the prioritisation of borderline cases increasingly difficult.

The experience of being in hospital

Stigma and discrimination

Compared to case studies of discrimination in accident and emergency departments and primary care services, there is little evidence to show high levels of discrimination against homeless patients whilst they are in hospital. A patient's homeless status is to some extent masked by his or her new patient identity. However, people who have been sleeping rough for many years often find the hospital environment very difficult to tolerate.

High rates of self-discharge amongst homeless people to some extent illustrate their dissatisfaction with the hospital environment or treatment received. Acute services – and the medical model of treatment – largely fails to address social and psychological aspects of care. It should also be noted that better primary and preventive care would make admission to hospital unnecessary in many cases. Better care could be better provided in a less institutionalised and less clinical environment.

Personal necessities

Often homeless people are admitted without money for personal necessities and therefore rely on social work assistance to make a benefit claim. Comments from nursing staff, such as "they are very good at reminding us", as well as anecdotal evidence suggests that referrals to social workers concerning financial problems often rely on patient requests or "reminders". This is a cause for much concern and anxiety amongst patients. It should be recognised that it is not only homeless people who need this kind of advice and assistance when they have been admitted to hospital and it should be seen as integral to someone's overall care. The onus should not be on the patient to have to insist that these needs are recognised and support given.

Preparation for discharge

Difficulties in making appropriate discharge arrangements for someone

who is homeless may mean that they stay in hospital longer than someone who is securely housed. It is important that they stay in hospital until they are fully recovered if appropriate accommodation cannot be found. However, people who are in hospital for some time are at greater risk of secondary infections, may become institutionalised and, because they no longer require acute medical interventions, their needs are often ignored. The pervading sense of uncertainty surrounding discharge arrangements may mean that opportunities for rehabilitation and discharge preparation are neglected.

The risk of peoples' needs being overlooked in this way is increased on busy surgical wards, and teaching hospitals (Dove, Dove and Gerard, 1986). Attempts to link unregistered patients with GP services – even to facilitate follow-up through specialist services – are extremely rare and ward staffhave very limited knowledge of the range of services available to homeless people (Green, 1991). Often due to unsatisfactory discharge arrangements, records of a person's contact address do not exist. Difficulties then arise following patients up in the community or if they need to be informed about outpatient appointments.

Homeless people should be given outpatient appointments before they leave hospital. It should also be recognised that it is often difficult for homeless people to make appointments at a fixed time and this should be taken into account when they attend, as it is for people arriving by hospital transport.

It would seem essential, given the current move towards community-based services, that there is an urgent need for more comprehensive training on discharge management. In addition to this, information about the range of statutory and voluntary agencies in the community should be available to acute sector staff.

Leaving hospital

Pressure to discharge

Increased pressure for fast processing of patients clearly discriminates against single homeless people. Interviews with ward sisters at one hospital indicated that nursing staff try to take on responsibility for ensuring "safe" discharge. This can involve taking a stubborn line with doctors who are anxious to empty the beds. Successful negotiations often depend on whether an established working relationship exists between the nursing staff and doctors. Team co-ordination is made more difficult in wards where there are as many as eight different firms attached – plus a number of outlying emergency admissions from unfamiliar firms.

It is the doctors' responsibility to authorise discharge and so ultimately "when they say get the patient out of that bed immediately, there is nothing we can do". The nursing staff who were interviewed expressed much concern about the current bed crisis and the frequency with which people are discharged without appropriate accommodation or support. It is also clear that staff shortages make it difficult for nurses to spend time considering someone's social needs.

Agencies working with homeless people are also concerned that their clients are discharged with little thought for their aftercare needs. One worker told us that an elderly man was put into a taxi in his pyjamas and sent to the homeless persons unit. "The HPU was closed, but he managed to find his way to our door where he had stayed some months previously". A frequent complaint was that hospitals were sending people to agencies without making sure that there was a bed for them, let alone whether they would be able to receive appropriate care. A nurse in a resettlement unit was "speechless" when a ward sister contacted her to ask if there was piped oxygen available in the hostel.

This hostel is probably fairly typical in that it provides a basic shelter and nothing more. Yet hospital staff seem to refuse to accept this, all they want is a clear conscience that they are not discharging people onto the streets. If they can send them to us then it becomes our problem, not theirs.

This nurse then gave the following example of an inappropriate discharge referral:

A thirty-year-old man living with us has become unwell and was diagnosed as having renal failure. He had been in hospital for a period of about three months, after which he was commenced on kidney dialysis treatment.

We received a visit from the hospital social worker who was very keen to discharge him back to the resettlement centre. This man was going to need a lot of support, as he would have a permanent catheter just above the pubic bone, through which, three times a day, he would have to put in, and drain out, some three litres of special fluid.

The main concerns were firstly hygiene, in that all the bathrooms and sinks are filthy in the extreme, and the possibility of infection would be a real problem. Also the storage of the large amounts of the fluid he would need; plus it was felt that he was not the sort of man who would ask for help should things go wrong. All in all it was felt the risks involved were too great and that this man deserved more support than he would receive here.

Responsibility for discharge

DoH guidelines for discharging patients from hospital, (Circular HC (89)5) state that: "Special care must be taken in planning discharge arrangements for ... patients suffering from psychiatric illness ... people who are homeless or live in hostel accommodation". The circular goes on to state the specific responsibilities of different team members, and requires the designation of a key person to co-ordinate discharge arrangements.

These guidelines lack clarity about responsibility and accountability. It would seem that in reality discharge protocols vary from one ward and hospital to another. Dissemination of official discharge policies to frontline staff is also lacking. Only one of the staff interviewed was aware that the health authority *had* a discharge policy statement; none had ever seen it.

In 1990 the Medical Campaign Project did a survey of all mental health units in London to find out if they had produced discharge

procedures in line with DoH guidance and how appropriate these were for homeless people. Only one health authority among the eighteen that responded had a specific discharge policy for homeless people. The vast majority of the others did not even mention homelessness.

Where there are policies that should protect people from bad discharge there is often a yawning gap between policy and practice. Section 117 of the 1983 Mental Health Act is supposed to ensure aftercare for all patients who have been detained under a section of the Act. To work efficiently there should be a meeting between all hospital staff and staff in the community who are taking over a person's care. In practice a co-ordinated meeting of all agencies involved to discuss aftercare rarely seems to happen. The Medical Campaign Project was told of one consultant who, at the end of a ward round when he had decided to discharge someone, says: "Well we'll call that the Section 117 shall we?". This type of attitude makes a mockery of planned aftercare.

It is clear what a good discharge procedure would be, and this has been well documented. From April 1991 Mental Health Units should have developed a care programme approach, which should apply to everyone discharged from psychiatric care. If the requirements of this approach were being fulfilled people would not be leaving hospital without support set up for them. It is, however, crucial that care packages are planned in the context of peoples lives. As a worker at the Compass Project said: "People are set up to fail, if they offer a package that doesn't meet users' needs they are bound to get out of contact".

Homeless people are clearly discriminated against through poor management and liaison. One social worker complained of instances when she was given one hour's notice before homeless patients were due to be discharged:

you know the ward rings and they say "we've got this man and he's ready to go". And you've never heard of him ... so we generally say "send him down" and do a very rapid assessment, because they're not going to put him back in a bed.

In these cases, social work referrals are no more than a formality. The lack of real accountability for discharging single homeless people may stem from the assumption that they have no power to seek redress, and there will be no complaints from relatives or carers.

The guidelines from the DoH bear no relation to the actual resources necessary for realising the ideals they contain. Social service cut-backs have led to a situation where a number of consultants' firms are left with no attached social worker. These include patients in geriatric, psychiatric, alcohol and drug detoxification and accident and emergency intake beds. These wards admit a proportionately higher number of single homeless patients.

It is also essential that the roles and responsibilities of different staff in the discharge procedure are clearly defined. The discharge plan should not be just the work of one agency but the result of co-operation and liaison between different agencies and workers with clearly identified roles. Communication both between hospital-based staff

and with agencies in the community is crucial to planning effective discharge and preventing unnecessary readmissions. The following case study from the Primary Care for Homeless People Project illustrates the problems which arise when care is not co-ordinated:

Nicola is a diagnosed schizophrenic who also suffers from epilepsy, has a long history of mental illness and suicide attempts. She is 29 years old and is currently eight months pregnant.

She has had repeated admissions to St Pancras but has always run away. She does not have a CPN and it is not clear who should be administering her medication. She was advised to go to Great Chapel Street for her fortnightly injections but unfortunately she fails to attend. It is clear that her symptoms are no longer being controlled, hence her repeated readmissions to St Pancras. It is hard to believe that an eight months pregnant, mentally-ill woman can be expected to find her way across London for her medication. She has been assigned to a community midwife but she has not had any domiciliary visits. She is expected to attend antenatal care at UCH which she fails to do.

Many people are involved in her care, but this care is unco-ordinated. A key worker is needed to avoid duplication and to ensure the reversal of this overall failure to support her in the community.

It was clear from interviews with social workers that pressures generated by their priority case load often leave single homeless people out of the picture. Minimal assistance may be given by way of money for taxi fares and a somewhat inaccurate list of emergency accommodation – "It's the least we can do ... although they'll probably go straight to the pub and drink it". A recurrent theme was that basically ".. there's really not a lot we can do". If anything, the pressure they are under has a negative affect on their attitudes towards homeless people.

Nursing responsibility

The effect of social workers having a statutory responsibility for the elderly and for children is that nurses are often left with the responsibility of organising the discharge of single homeless people. In some wards a "primary nursing" model is used where a qualified nurse is responsible and accountable for the care of designated patients during their stay. This introduces greater continuity of care, and the nurse will be responsible for planning and organising a person's discharge and aftercare. This system contrasts with standard ward management where senior nursing staff are equally responsible for patients on the ward. However, it can only work effectively when there is a full complement of staff on each ward and too often this is not the case.

Inverse care laws in hostel provision

Social workers' main grievances lie with the lack of available hostel accommodation for homeless people, especially people with severe medical, mobility, incontinence and/or dementia problems. Sometimes problems arise when a hostel refuses to take a client back. This may happen when staff feel they can no longer care for the person

adequately. Criteria for acceptance within hostels vary, but there is clearly an acute shortage of provision for people with high dependencies; for people with severe behavioural problems, alcohol or drug dependencies and for people with mental health problems. The range of accommodation available and acceptable to women and people from minority ethnic groups is also very limited.

The following description shows the perspective of the health care co-ordinator at one of the few hostels providing high-dependency beds:

With a ground floor that has become a virtual nursing home and not a long-stay hospital bed/nursing home placement/Part III vacancy in sight ... what am I to do with my blind, doubly-incontinent, demented residents? ...

It's a while since I've refused to "take somebody back" - when you do, you require nerves of steel. It is obviously extremely bloody and inevitably the patient will end up on your doorstep one way or another. Hospital social workers are often not available and the wards don't have the resources to know what to do. Everyone is desperate ... THERE ARE NO BEDS. The whole thing is horrible ...

What is very clear is that people are getting discharged back to "the community" with greater and greater needs than they were previously when alternative long-stay beds were available. Wards have little or no idea how to implement a "Community Care" service prior to discharge. Surgical wards particularly, barely give it a thought. I think most nurses think things just miraculously happen when the patient gets home. The urgent need for hospital beds, and the pressure put on nursing staff by the medical team to discharge, makes a total mockery of good discharge planning. There never seems to be enough time for them to do it, and I genuinely feel that it is not prioritised nearly enough. It should commence from the time of admission to the ward and clearly DOESN'T ...

From my perspective — a hostel-based one — I am screaming out for alternative long-stay placements. There are none in sight. Quality care in the absence of full-time (exhausted and exploited) carers, it seems to me, is in many cases virtually impossible unless appropriate alternatives are found. If this means a return to long-stay care...then so be it. So be it too for the sake of the carers, who are meeting an early grave themselves as a consequence of their "caring in the community"... Bad press and poor track record should not mean the end of long-stay alternatives for those who need it. It should mean change — and it clearly does, but is the present situation of "Community ("own home") Care" the only solution? ... Good alternatives don't however come cheaply ... there is no doubt that this is the real crux of the problem. Without adequate money — nothing in this article will be achieved.

(Becky Boyton (Health care Co-ordinator) SRN, RMN)

Criteria for discharge are based on whether a person continues to need acute medical treatment, rather than whether they will receive adequate care when they leave. There is a need for more long-stay and low-dependency beds where people can convalesce and be given

appropriate support and rehabilitation. There is also a need for community beds, both for people who are essentially "social admissions" and for people with on-going convalescent needs who lack accommodation and/or carers, for whom care at home is thus an impossibility. Greater emphasis must be placed on a person's continuing care needs and the circumstances to which they are being discharged. Social workers must be attached to each ward and be an essential part of the ward team to ensure that a person's social needs are not overlooked.

Liaison with homeless agencies

A common complaint from homeless agencies is poor liaison and communication from hospital staff. The problem lies partly with the failure of hospital staff to perceive agency workers as the relevant "carers" where no other support exists. It is particularly acute in agencies where large and growing numbers of clients are elderly, or are suffering from mental health problems. Essentially, this means that agencies entrusted with the "care" of an individual may receive little or no information about a client's condition, treatment or continuing care needs.

Tom, aged seventy years, had been living in a hotel in Camden for several months when he was admitted to hospital for TB of the lung. On discharge he was sent back to the hotel. Two weeks later PCHP received a call from the hotel manager who needed help getting Tom's prescription renewed. We visited the hotel and found that Tom was very distressed because he had not had any tablets for four days since his prescription had run out ...

PCHP phoned his GP, the hospital and the chest clinic: it was clear that no-one thought Tom was their responsibility. There had been a complete breakdown in communication between acute and community services, resulting in a total disruption of care for Tom. The only care Tom received was from the hotel manager and other residents.

(Primary Care for Homeless People)

A new client was booked in and I was asked to see him. It appeared that he had just been discharged from hospital after a coronary bypass graft ten days before. He was very breathless and he told me he had asthma. He had with him a small bag of pills, but he had no idea what they were or why he was prescribed them. He also had a suture line from the base of his throat to his pubic bone, which had a small open area around his naval.

As there was no note with him, nor had we been advised of his discharge, I rang the ward he had been on. The nurse that I spoke to said the man had "gone home". On being asked where that was she admitted she did not know. I then asked her about follow-up arrangements and she did not know anything about that either. A formal complaint was made about this discharge which we felt to be inappropriate and badly managed.

(Nurse in hostel)

For individuals who are vulnerable, or too ill to cope alone, lack of information and support inevitably affects the carers' capacity to provide support to individuals, and facilitate their follow-up.

Information relating to a person's stay in hospital is often deemed to be confidential and cannot therefore be passed on by phone or in writing to non-medically trained staff. This means that agencies entrusted with the "care" of an individual may receive little or no information about their client's needs, which inevitably affects the agency's capacity to support that individual and facilitate their follow-up care. It is not suggested here that patient confidentiality should be violated, but that flexibility and attention to individual needs should be the key. With a little extra time and trouble, important information can be passed on with a person's consent.

Because this information is not systematically passed on to carers it tends to be received indirectly, through patients' own initiatives or through the efforts of concerned agency workers. It is the hospital's responsibility to initiate such liaison (DoH guidelines, 1989b) although this is typically left until discharge is imminent, if it is done at all. It was a constant theme from homelessness agencies interviewed that if there was any liaison it was always up to them to make the effort, make the contact and stay in touch. The initiative very rarely comes from the health authority:

We always approach the ward, we always phone, ask them to write our number in the case notes. We ring every week to ask how the person is getting on and ask them to ring us about anything. Nine out of ten times they don't. It's very one-way, very frustrating. They never even tell us when they discharge people, let alone ask us to a Section 117 meeting. (Worker from the Compass Project)

It was the experience of most of the agencies contacted that discharge was not a question of the person's readiness to leave hospital, but a question of their bed being needed by someone else. Only one said that in their area someone would never be discharged on to the street from an inpatient bed. In other areas there were examples such as the following from the Lambeth Walk-In project:

A user of the centre was in hospital for two-and-a-half months; on leaving he was given his fare into town and arrived at the Walk-In in a terrible state. We rang the hospital, the social worker agreed that he wasn't fit to be discharged but said that there were limited beds and as soon as people improved they were moved on.

The community psychiatric nurse (CPN) with the East London Homeless Health Team (HHELP) team feels that his involvement can influence discharge and that people have been kept in hospital until somewhere suitable is found for them to go due to his contact with them and with the hospital.

Assumptions are often made that people living in hostel accommodation will be accepted back, without any prior warning or consultation about discharge plans. Uncertainties of this kind can cause a great deal of anxiety for patients as they are aware that hospital staff have little knowledge about hostel organisation and such issues as the necessity of securing beds. Moreover there is a lack of understanding about the levels of support and facilities hostels are able to offer, as well

as the variations that exist between forms of emergency and long-stay accommodation.

The urgency of "finding somewhere" for a patient may simply be a case of establishing an address, without proper assessment of its suitability or appropriateness. Patient choice is to some extent limited through the lack of options available. However, it is often the case that patients who decline hostels arranged on their behalf are often assumed to be "obstructive" or "difficult". Often it is assumed that patients declining hostels are choosing to return to the street. Although this may sometimes be the case, the stereotype is an extremely dangerous one.

The HPU

An admission to hospital often dramatically alters a person's housing situation. People lose rented accommodation, or if they are in a hostel, they might lose their bed. It should be the case that a stay in hospital means that a homeless person will get help to find appropriate accommodation and be linked in to services in the community.

The information needed to indicate that a person is homeless is recorded when a person is admitted. The social work department should be informed straightaway if someone does not have an address to return to. Discharge planning should start from the time someone is admitted so that there is time to find the most appropriate accommodation within the resources available.

It is obviously easier to arrange the discharge of a person who will be accepted by the HPU as in priority need and social work departments tend to concentrate their energies on those people. However, it is still common for people to be just sent with a letter to the HPU, without any previous contact having been made. Others who do not get prioritised by the Homeless Persons Act miss out on help and advice. Every effort should be made either to ensure that where appropriate people are accepted by the local authority as vulnerable or that other appropriate accommodation is found.

Providing that a person fits the categories of priority need (in the case of single people without children, that they are elderly or vulnerable for reasons of ill health) they can be accepted as homeless by the HPU if they are going to be homeless within twenty-eight days. People should not be sent to the HPU when they have been discharged: contact should be made as early as possible so that the process can be started of assessing their need and finding accommodation. HPU staff should also be willing to visit wards to assess people there. The level of the support the person needs in the community should be discussed and arrangements made for a day centre place, a CPN or a district nurse, a sheltered employment scheme, a home help or whatever is considered necessary.

It should be emphasised that the issues of accommodation and health and social service provision are inextricably linked. For example, if someone is accepted as vulnerable for reasons of mental ill health they may then be placed in very unsuitable temporary accommodation. Even for those who are permanently rehoused, there are no

adequate support structures in the community to help them cope with independent living.

The definition of who is vulnerable for reasons of ill health is open to interpretation and varies enormously throughout London. It is almost always done on a medical assessment; this means social factors tend to be ignored. The nature of the assessment often means people without a GP cannot produce the required evidence so do not even get assessed.

Mounting criticism of these procedures indicate the need for a thorough review of medical assessment procedures. These decisions should be made by a multidisciplinary panel with the emphasis shifted away from medical criteria. This panel could also make decisions on a person's need for support so that vulnerable people do not continue to get placed in highly inappropriate bed and breakfast accommodation or isolated independent flats with no support systems. An overhaul of the present system could provide a basis for health and housing sectors to work together more effectively to meet peoples' needs.

Criteria of vulnerability according to ill health or old-age can be over-ruled by stipulations of "intentional homelessness" or by denying that someone has a local connection with the area they have applied to. Both of these requirements in the legislation often seem to be used to evade responsibility. People who already have an established street "way of life" tend to be placed into one of these categories. The following extract illustrates that priority need is not necessarily established by age and illness criteria alone.

Jim had extreme difficulty walking as a result of his ulcerated and gangrenous legs, he was doubly incontinent and he was starting to suffer from senility. It was clear that Euston station could not be home for him for much longer. So we took him to the HPU in the hope of getting him accepted as vulnerable under the Act and being offered a place in an old people's home. But no, he was refused on the grounds that he was a "wanderer". We were stunned. "A wanderer! but he's got a fucking walking frame. How can he be a wanderer when he can't even walk without a frame?". But it was to no avail. Not long after that Jim vanished from Euston Station, and not even the station guards had any idea where he had got to. He's probably dead now...

(Ansell, 1989)

The whole concept of intentionality is pervasive and dangerous. It is prominent in housing legislation and practice and is also an issue in health service provision. In 1989 the Bloomsbury Health Authority issued a response to the CHC's report *Homeless and Unhealthy in Bloomsbury* (Medical Campaign Project and Bloomsbury CHC, 1989). It contained the following statement which is deeply offensive and largely inaccurate:

... there are two differing problems – that with the single homeless who may choose to some extent their lifestyle they lead and that of homeless families who have been placed within the district from a wide pattern of referrals.

(Minutes of the statutory meeting between Bloomsbury CHC and Bloomsbury health authority, July 1989)

People very rarely choose homelessness as an option. It would be more appropriate for service planners to focus on the pressures that cause and maintain homelessness rather than concentrating on strategies which enable them to evade responsibility.

CHAPTER



Acute mental health services and single homeless people

his chapter examines the link between homelessness and mental ill health and the appropriateness of the response of acute mental health services. Looking at aspects of care from admission through to discharge, it will be shown why so many homeless people in need of psychiatric help remain out of touch with services. For the purposes of this working paper contact was made with forums of mental health service users, and additional information was taken from documents written by users, many of whom had experienced homelessness.

Much of the research done in the area of mental health and homelessness has been carried out by people who subscribe to a medical model of mental health. The authors of this paper subscribe to the view that mental ill health has its roots in people's social experience, not in chemical imbalance in the brain. Diagnostic labels, such as "schizophrenic", are referred to only when they have been used in the research that is mentioned. We accept the validity of a perspective that rejects this type of labelling.

There is a constantly reiterated phrase when talking about homeless people and health care: this is that people have "fallen through the net". As O'Neill has stated (1988), "they are truly the forgotten men and women who have fallen through every net society has to offer".

This section re-examines this idea of a net. Caring for People, the DoH White Paper (1989) on community care, claims that "most commonly homeless people have had care organised outside hospital but have lost touch with services". If this is the case, part of the answer must be to look at the appropriateness of the services on offer. As Jowell said in her speech to the "Policy into Practice" conference (January 1991), "safeguards must be built in so the most vulnerable do not appear to be those who opt out of services".

Health service professionals often interpret the idea of safeguards as, for example, a computerised system which enables service providers to trace people across different districts and different services. In this way doctors have information on a person's last contact and last treatment.

A more appropriate way of interpreting this idea of safeguards would start by listening to the most vulnerable users of health services about what their needs are and gearing services to meet these needs. This would make it much less likely that they would "fall through the net". As Sayce (1991) has argued:

An alternative approach ... would be to assume that many people "slip

through the net" either because key components of the net are missing – for instance housing – or because they have opted not to use services they do not like.

This chapter aims to show that this net is inadequate and that the medical model in which mental health services are based fails to meet the needs of users and particularly those who are single and homeless.

Homelessness and mental health - myth and reality

Homeless people with mental health problems have become a focus of government and media attention in recent months. The popular view is that large psychiatric hospitals are closing down, that care in the community is failing this population and that people who have been long-stay patients are ending up on the streets. There is little evidence to corroborate this theory.

People leaving long-stay hospital tend to be involved in well-planned resettlement programmes and only a very small percentage become homeless (North East Thames Regional Health Authority Team for Assessment of Psychiatric Services (TAPS), 1990). There is evidence however that people who have been admitted to acute psychiatric beds are likely to be discharged to large hostels for homeless people or to no fixed abode (Hatch and Nissel, 1989; PTSHP, 1990).

Research that has been carried out amongst homeless people has shown that many of those with an identified mental health problem also have a history of admission to psychiatric hospital, but in general this is a history of short, maybe multiple admissions, rather than long-stay admissions. This was also the experience of the agencies contacted by the Medical Campaign Project for the study on which this chapter is based.

Among the group seen by the PTSHP, forty-two per cent had spent less than a year in a psychiatric hospital; thirty per cent had spent more than two years, with about a half of these having spent more than five years in total. One of the recommendations in PTSHP's final report is that:

the reductions in acute and medium-stay beds be publicised to counteract the current myth that the increasing numbers of the homeless mentally ill are solely related to the closure of long-stay beds.

(1990, p.127)

In 1987, a study of long-stay residents in resettlement units showed that in three of the units, each of which house between forty and 150 men, people who had a history of multiple admissions to psychiatric hospital were a very significant category, but there were only six men across all three resettlement units who had been inpatients for more than six months. The study concluded that:

it is therefore clear that there is no evidence whatsoever that former longstay psychiatric patients are ending up, either by design or default, as longstay residents in the resettlement units.

(O'Neill, 1988)

Mental ill health and homelessness - cause or effect?

It is clear that there is a link between mental ill health and homelessness. The nature of that link is a more controversial issue.

It is obvious that becoming homeless is a profound loss, which may be classed as a severe adverse life-event. Life events, especially losses, have been demonstrated to be of causal importance in psychiatric disorders like depression.

(Faculty of Public Health Medicine, 1991)

Very often people have become homeless as a result of other losses in their life, the loss of a partner or a job, or they have left very painful situations where they have been subject to violence or abuse. The experience of homelessness itself puts enormous strains on a person's mental health; this is most obvious for people living on the streets but it applies across every homeless situation.

In hostels, bed and breakfasts or sleeping on friends' floors, all the human needs for privacy, self-expression, personal tastes, having friends to visit and sexual relationships are excluded because of the constraints of the living situation (Watson and Austerberry, 1986). In this context it is not surprising that estimates of the proportion of single homeless people who have mental health problems vary up to a figure of fifty per cent (Stern, Stilwell and Heuston, 1989; Williams and Allen, 1989; Single Homeless in London (SHIL), 1991).

As Kay and Legg (1986) demonstrate, a stay in psychiatric hospital often has a profound effect on a person's housing circumstances. An episode of mental ill health and hospitalisation can lead to a breakdown of relationships, loss of a job, loss of accommodation. Being discharged from hospital can be the beginning of someone's homelessness. In the absence of an effective community care programme, the lack of ability to motivate oneself associated with mental health problems and the stigma with which society, including landlords and employers, regard mental ill health, can mean that people end up living in very deteriorated circumstances and with little contact with services.

The homeless population and acute mental health services

As has been made clear in the rest of this section, it is very difficult to see acute services in isolation. This is particularly so in the case of mental health services, where there should be a very close interface between health care and social care. The aim here is to demonstrate that part of the problem is the inability of acute services to see people within their context and to recognise how profound an effect a lack of adequate housing has on a person's health. The medicalising of people's problems is a feature of acute services, yet homeless people are in a position of having to make "repeated use of acute services because of the barriers to more appropriate care" (PTSHP, 1990).

Admission to hospital

For various reasons a homeless persons' most likely route for admission into a mental health unit is through either an accident and emergency department, which may also involve compulsory sectioning under the Mental Health Act, or by committing minor offences and coming into contact with psychiatric services via the criminal justice system. A brief examination of these different routes of admission follows.

Accident and emergency services

There is much anecdotal evidence to show that peoples' experience of using accident and emergency services for admission for reasons of mental ill health is often appalling. As one user of services said, "Once they discover you don't have a physical illness they have an attitude of disdain, you are wasting their time".

Without exception, workers in homelessness agencies described accident and emergency departments as inappropriate places to take people experiencing mental distress.

the staff there are not geared up to dealing with someone who is in mental distress, they plough through a completely inappropriate form asking questions like "when did the illness start?" to someone who doesn't perceive themself as ill. Physically, its a very difficult place to have a long wait, there's nothing to do, the chairs are nailed to the floor. Homeless people experience stereotyping and prejudice, they often don't stick it out because of the way they get treated in casualty.

(Worker at the Compass Project)

Yet the lack of anywhere more appropriate means that these vulnerable people have no choice but to turn to accident and emergency departments for help. Again, agencies working with homeless people said they feel they must accompany users of their services to accident and emergency departments to ensure they receive appropriate treatment and care. A worker at Alone in London, a service for young homeless people, said they did not always accompany people, but the attitude was so punitive when their clients were accompanied by staff he could not imagine it being worse if they attended alone.

He gave an example of a young woman who had cut her wrists and who was stitched up with no anaesthetic. He felt that the attitude to her, and to their clients who had overdosed and had their stomachs pumped, was one of making the treatment as unpleasant as possible with the rationale that this would prevent a recurrence of the incident. As he remarked, "this is an extraordinarily primitive view of working with people with mental health problems". Similar experiences have been documented by Diblin (1991), who concluded "the experience of these women was that even though they had tried to take their own lives no-one was interested in helping them".

Waiting times in accident and emergency departments are a constant source of problem for people. Most agencies had experience of people who they felt needed admission and who couldn't cope with the process of waiting. In one incident a hostel worker had accompanied a woman in a very bad state: they waited many hours and

eventually left intending to return the next day. The following day the woman threw herself under a car and died on the way to the department.

Waiting times may be a little improved if the agency has links with the psychiatrist. If a phone call is made and the duty psychiatrist expects the person the process can be speeded up, but even then instances were reported where the wait was too long and the person left before being seen.

Agencies and users in an area served by an emergency psychiatric clinic felt better about the quality of psychiatric care they received. It obviously made a big difference going somewhere where the staff were trained and expecting to deal with mental distress. Unfortunately only the Maudsley Hospital provides a twenty-four-hour emergency psychiatric service.

Accident and emergency departments do not offer a mental health service. They can be a route of admission into hospital, but at the point of entry they only serve to increase people's distress. There is clearly a need for twenty-four-hour psychiatric clinics to be available in all districts. However, there is also a need for a range of services for people with mental health problems in the community, particularly in "non-medicalised" settings.

Section 136 of the Mental Health Act

A major route of admission into psychiatric hospital for people who are homeless, and particularly for African-Caribbean people, is under Section 136 of the 1983 Mental Health Act. This gives the police power to detain people who appear to be mentally disordered in a public place.

MIND have recently done extensive research into the use of Section 136. This showed that people from the African-Caribbean community are over-represented as a proportion of those detained under this Section. This is a particular concern shared by agencies providing services to black people:

There is mass criminalisation of people who are black and mentally ill. Most of our users have come into contact with the police, either through being picked up under Section 136 or because they have committed minor offences, such as stealing a can of coke.

(Worker at the Fanon Project)

There is some evidence to suggest that racism in the police force underlies this, but the general public is also implicated as it is often individuals who contact the police. Homeless agencies have also said they will occasionally resort to contacting the police to use their powers under Section 136 when they could not access any other route to acute services for someone in an emergency. Yet the police have very little training in, or understanding of, mental health and consequently are likely to use more restraint than necessary. It is the too-common experience of the black community that restraint is used in a punitive way.

To be detained by the police and taken to a police station or put in a cell is clearly a very distressing experience. Section 136 is a section for assessment, not admission, so being taken directly to a hospital also has its problems. There needs to be a serious review of how this Section is used, including the training police officers receive. There is also a need to develop codes of practices locally with the health and social services. An appropriate "place of safety' should be identified where speedy assessment of people detained under Section 136 can take place.

The courts

Another route of admission to acute services is through the criminal justice system. Research has shown that there is a large number of people in prison or on remand who have committed minor offences as a result of being homeless and mentally ill. A small number of initiatives have been set up at magistrates courts to divert people from custody into more appropriate care and these have proved very successful.

The Government is currently reviewing health and social service provision for "mentally disordered offenders". It is hoped that this will make urgent recommendations as there is clearly a need for a change in the pattern of service provision and for additional resources to be made available.

The pressure on acute services

The much-publicised closure of long-stay institutions inevitably puts more pressure on acute services. Yet relatively little media attention has been paid to the closure of large numbers of acute beds in London. It is against this background that the difficulties faced by single homeless people in gaining admission to hospital must be seen.

In Bloomsbury twenty-five per cent of the acute psychiatric beds have been cut since 1989 in order to develop services in the community – plans for which were then postponed due to a lack of cash. A telephone survey of the forty-eight acute psychiatric units in Greater London in April and May 1990 showed that the total bed occupancy in many districts was one hundred per cent or greater. This means that:

Widespread pressure on beds and overcrowding allows less scope for admission of other than the most severely disturbed patients. A case can be envisaged in which the most needy are denied access to emergency care.

(Hollander, Tobianski and Powell, 1990)

Workers in homelessness agencies would say that this case had already arisen on more than one occasion. Even members of the medical profession working in specialist projects for homeless people encounter problems in getting their users admitted and have to use accident and emergency departments. The PTSHP team report that:

There were difficulties arranging admissions, especially when the team was without a doctor, as previously his word had seemed to carry weight with the admitting doctor. Of the rest of the team, the nurses found admissions easiest to arrange, especially if they knew the duty psychiatrist. This seemed a clear example of needing to be part of the system in order to use it, and helped the team understand the frustrations and sense of rejection experienced frequently by hostel staff attempting to arrange an admission.

There were frequently times when it was impossible to find a bed, and cuts in acute beds were clearly having an impact on services.

(1990, p.115)

Workers in homelessness agencies felt that hospitals were reluctant to admit their clients because they were aware that being homeless they would have nowhere to go and be difficult to discharge. These agencies also felt that increasing pressure on beds meant a more restrictive attitude about the kind of patients who should be admitted in the first place. As one social worker said:

Services are geared towards sorting people into various pigeonholes – if they don't fit neatly it's much more difficult for them to get care.

This approach has been noted in other reports. Services for Homeless People, a report for Bloomsbury and Islington Mental Health Unit (Harris and McHugh, 1991), lists specific groups who have difficulty in gaining access to mental health services. This includes people who have alcohol and drug dependency problems and people labelled as having personality disorders. Kay and Legg (1986) quote a consultant from admissions:

We now have a radically different approach to admissions. We only admit people we feel we can treat as psychiatrists. There are many chronic conditions we can't treat.

As Satchell (1988) has argued, services are increasingly geared toward the needs of service providers, in particular to what medicine sees as important and relevant, rather than the needs of users. There is also an emphasis on "getting results":

When there's a limited number of beds they choose people for whom they feel they can make a difference, who won't show up again with the same problem in a few months.

(Worker from Lambeth Walk-In)

This type of policy obviously excludes large numbers of people from hospital. Hospital may not be the most appropriate place for them, but cuts in acute services have not been replaced with any other form of provision. Therefore people who were previously able to access a hospital bed when in need of asylum and care are left without anything.

Most studies show that homeless people frequently have a multiplicity of problems. Thirty-two per cent of the client group whom PTSHP were working with were alcoholics and the same percentage had chronic health problems, in addition to their mental health difficulties. O'Neill (1990) reported similar findings from her research into the health of men in resettlement agencies.

The NHS has a very poor response to people with more than one aspect to their ill health. They are more likely to get excluded from treatment or, if they are treated for mental health problems, their physical health is ignored and vice versa. The DoH has made it clear to the new mental health outreach team in the North West Thames region working with homeless people that it is expecting them to work with people with serious mental health problems, not

people with drug or alcohol problems unless those are secondary. This is clearly an absurd dividing line. How is it possible to know which is the secondary problem? The logistics of this aside, it is another example of people with drug or alcohol dependency being excluded from services.

Mental health - the user perspective

Users of mental health services have an identifiable voice. There are now many existing groups of users and ex-users trying to make that voice heard by the health services. One view that comes across strongly from the user's movement is a rejection of the medicalisation of their distress. People feel that they are given disabling labels and that the only treatment on offer is drug therapy. The specific needs of homeless people in relation to mental health services relate to access to acute care and problems on leaving hospital. Their experience in hospital is not significantly different from the housed population. Here the experiences of users who have been inpatients in psychiatric services are documented.

The biggest challenge to existing mental health services is to provide a service that responds to users' needs. The overwhelming experience of people who have been inpatients in psychiatric services appears to be one of not being listened to. This is in the context of the greatest need that is expressed by people experiencing mental ill health being the need to talk. The following comments are typical of peoples' experience:

My whole experience of psychiatry has been that they never listen. They never actually listen to your experience, they impose what they think is best and there's no chance to talk about what you're actually feeling or even your own feelings about why you've had a breakdown in the first place.

I needed a bit of reassurance, I got medicine, injections.

A person who is distressed is not always verbally articulate and therefore the availablity of therapies such as massage would be of great benefit in times of crisis.

A fundamental problem the health service has to tackle is its inability to perceive and respond to difference. Londons' population is multiracial, multicultural, people are from different classes, people have different sexualities, can be single parents, housed or homeless. With a few exceptions, the mental health services seem to be unable to respond to these differences in people's lives, or to see people in the context of their lives.

Workers from black projects in particular felt there is often a total lack of understanding of their client group. People who they know as being very gentle have been treated with fear and apprehension by mental health services simply because they are large black men and the service providers subscribe to a stereotype that assumes they are therefore violent and dangerous.

The prevalence of stereotypes such as these continues to mean that the black population has less access to talking therapies and are more likely to be given high doses of drugs to control their symptoms.

These concerns are now well documented and it is time the NHS looked seriously at this area.

To provide a mental health service that is appropriate and acceptable to users, the NHS must radically alter its practice and start from where people are in their lives. Many agency workers felt that health workers lacked understanding about peoples' lives:

They approach people from a problem-orientated medical model, even if it's not a medical problem. They need to develop a willingness to listen, to understand what a person's world view might be about, what it means to be homeless or black ... Mainstream services won't take racism on board, racism is institutionalised in the health service.

(Worker at the Fanon Project)

No effort is made to see these women in their context – they get stereotyped as being very difficult, not compliant with treatment.

(Marshall, 1990)

Users of mental health services are not a homogenous group of people, so there is not one users' perspective on inpatient services. There is, however, a wide consensus on the need for alternatives to the medicalising of peoples' distress and a halt to the attitude that treatment is synonymous with the prescription and administration of medication.

The treatments I've had are drug treatments which just numbed me, I couldn't get in touch with my feelings at all, I was just going round like a zombie.

They never told me I was not obliged to take the medication. It was forced on me.

Many users feel that they have had a need for, and been helped by drug therapy, but there is widespread concern about the lack of information that people are given about side effects and the lack of support they are given to reduce dosages or come off drugs once they have started to use them. People also experience drugs being used in a punitive way and being threatened with compulsory treatment if they do not comply voluntarily.

Hospitals tend to put considerable pressure on people to take medication, although its benefits are rarely fully explained.

Sometimes physical force is used where talking and explanation would have been effective.

(Camden Consortium and Good Practice in Mental Health, 1988)

The whole system in psychiatric hospital is one of disempowerment, when in hospital people are not allowed to make choices about whether drug therapy is what they want.

On admission to hospital people lose much of their past history, along with personal belongings, their responsibility as an adult, and their rights to privacy and information. Many feel they have been reduced to a set of symptoms.

(Ibid.)

Some agencies said they felt that psychiatric wards were so short-staffed that keeping patients warm, fed and given medication was as much as they could do. Given the total lack of counselling or real exploration of people's problems, workers felt there was little point in trying to access hospital beds for their users. As Islington Mental Health Forum has stated (1989): "The human problems and conditions which may have precipitated the person's stay in hospital are not given any space to be explored".

It obviously takes more time to offer patients counselling, massage and time to talk rather than drug therapies, but existing resources could be used in a more effective and sensitive way. Mental health services have to look at how often they fail to meet the needs of users.

Leaving hospital

Failure to address people's mental distress in terms of their life experiences and circumstances means the effect and implications of a person's homelessness are not adequately dealt with during their stay in hospital. This may also mean that inappropriate follow-up and support is available to a homeless person on leaving hospital. There is now considerable research to show that people discharged following a shorter stay in psychiatric hospital do not get helped with appropriate accommodation and more than half are discharged on to the streets or to hostels. (See for example Hatch and Nissell, 1989; Stern *et al.*, 1989; PTSHP, 1990).

The importance of ensuring that appropriate accommodation, support and aftercare are available to homeless people on leaving hospital has been emphasised earlier in this working paper. To this we would add the need to develop a range of preventative, therapeutic and crisis intervention services in the community to widen the choice available to users.

Good practice

Many users and workers in homelessness agencies and mental health projects when asked for illustrations of good practice could only think of isolated examples.

A worker from Alone in London talked about Northgate clinic, a specialist adolescent unit with a range of therapeutic activities to suit individual needs such as drama, art and counselling as well as helping people with drug and alcohol problems. It is a small residential unit that will accept people who are homeless and works with them to find appropriate accommodation. This sort of facility is all too rare and much needed.

The CPN with the HHELP team mentioned the Henderson as a model which should be replicated. This is a scarce resource that does long-term therapeutic work with people and is client-led.

It is yet to be seen how useful the new DoH-funded mental health outreach teams working with homeless people will be to this population. One of the teams in the north-west region has got underway; the others are only just beginning to plan their work as this paper is written. One problem that the North West Thames regional team has come

across already is that because they are working through established homelessness day centres, they are seeing an almost exclusively white street homeless population. It is hoped that ways will be found to overcome this and work will be done with people who are less visible and more out of contact with services.

A common theme from organisations contacted for this study is the need for projects to be established which are appropriate to specific groups whose needs are not being met by current mental health practice. It was felt that the black community get a particularly raw deal from existing mental health services. The aim would be to set up innovative pilot schemes to show that things could be done differently. Both the Forward Project and the Fanon Project were cited as examples of good practice and as innovative schemes meeting the needs of black people with mental health problems.

It was also suggested that women-only services should be provided. Many women with mental health problems have experienced abuse at the hands of men, and many women continue to experience abuse in hospital. In spite of the fact that women are the majority users of psychiatric services, hospital wards are often not an environment women feel comfortable in. It is important that there is somewhere that feels safe and where women can choose to be treated by women.

For everybody there is a fear that once they get into the psychiatric system they will have that label, experience the stigma of hospitalisation and only be offered certain kinds of treatment. Yet the reality is that there are few alternatives available. There is an urgent need for somewhere else for people to go for assessment and help when they are experiencing a crisis.

Barnet Health Authority have a unique multidisciplinary twenty-four-hour crisis intervention team. They will respond to calls from the police, GPs, carers or people feeling in need of help. The team try to avoid hospitalisation and to support people in their homes. If a person referred to them is homeless, they will help him or her get into temporary accommodation and continue to support him or her there. The team has shown itself to be a cost-effective service. The attempted suicide rate has declined, admissions have gone down and the drugs bill has been reduced. This is one model that should be replicated in other areas.

Crisis centres in the community that do not just work on a medical model view of mental health have long been something that mental health user groups have been lobbying for:

There are times in our lives when we feel a need for sanctuary. As an alternative to hospitalisation there is a need for a safe place with twenty-four-hour support, where people can withdraw from medication, and gain strength and support from having counselling or therapy; where people can talk about the difficulties they are experiencing in their lives in their own way.

(Islington Mental Health Forum, 1989)

We suggest that the need for a safe place of this nature is a priority, not only for homeless people, but for the whole community.

There is a substantial body of evidence that suggests that the experience of homeless people with psychiatric services has been such that they choose to stay out of contact with services. A member of Lewisham Users' Forum writes about another member who is now homeless:

He went through the same ward and the same horrors as I did in an old institution. Like me it leaves scars. His hospital experiences have left him with such dread he will not seek help from the system in any shape or form.

If we accept that people are deliberately out of touch with health services this is a serious indictment of the mental health system. There is clearly a need to develop mental health services which are accessible and flexible enough to meet the individual needs of a diverse population. There must be a variety of responses to meet the needs of single homeless people with mental health problems, including their social care and support needs. This means that mental health services should be less hospital-based and less grounded in the medical model. As one user has said:

The evidence of people who have been through the system cannot be denied simply because we have been through the system – we're talking about real issues, real feelings, real perceptions.

(MINDLINE, 1991)

A substantial amount of research has been done in this area and users of mental health services have made their voices heard. It is now time that the health service listened and changed its practice.

CHAPTER



Discussion

his section of the working paper has made clear that it is meaningless to consider acute service in isolation from wider issues, such as public health, housing, and primary health care. Regrettably, such factors are not reflected in normal patterns of acute service delivery; they are based on the assumption that users have access to adequate housing and registration with a GP. Perhaps more than any other user group, homeless people will experience direct and institutional forms of discrimination from admission through to discharge and aftercare arrangements. Although lack of accessible housing is the crux of the problem, this is no reason for health services to abdicate from their responsibility towards homeless people.

Whilst homeless people need better health care resources, the most valuable preventative health care resource which would substantially alleviate the problems identified, is appropriate, good quality housing. The health authority clearly has a duty to alert the Government to the serious public health issues of the homelessness crisis.

(Medical Campaign Project and Bloomsbury CHC, 1989)

Purchasing services for homeless people

Under the NHS and Community Care Act district health authorities must now "focus on populations rather than patients and *health* ... rather than the management of services" (NHS Management Executive, 1991). The first round of contracts entered into in April 1991 reflected the current use of services within a district. From this baseline it is expected that:

DHAs will be able to make an overall assessment of the health of the local population and establish local priorities. Their service specifications can then outline proposals for change as a basis for contracting ...

Needs assessment will provide material to highlight areas where changes to services may be needed and indicate the nature and direction of those changes.

These guidelines urge health authorities to establish a policy which will enable them to judge priorities for change and, where appropriate, seek a fundamental review of service delivery "where there is concern about the way in which a particular health problem is tackled".

The introduction of the contracting process provides a mechanism whereby purchasers could seek to influence the quality of services received by homeless people within their district. We have shown that services are failing to respond to the needs of this group of users and

these failings will be reflected in the current contracts based on existing patterns of use. Therefore health authorities should undertake to assess the needs of homeless people and seek a fundamental review of service delivery on the basis of this assessment. This must reflect the needs of hidden homeless populations as well as those living on the streets and in hostels. They should also make clear their commitment to serving this group:

There needs to be a clear lead from the top that homeless people are legitimate users of health services, a clear message to workers at ward level that homeless people are worthy of receiving treatment. There's still this attitude that they're there under sufferance, that they're non-deserving.

(A worker from the Compass Project)

Needs assessment

Quantifying need

Under the new arrangements for the funding of the NHS, district health authorities are allocated resources on the basis of their *resident* population. There is therefore a great deal of concern that adequate funding is not being provided to meet the needs of their homeless population and this has led many authorities to look at ways of evaluating the *quantity* of services used by this group, rather than issues of quality. As we have indicated earlier in this report, single homeless people are probably the most difficult sector of the population to quantify.

The view that statistical methods of quantification are a necessary prerequisite to resource allocation, has traditionally delayed action. Within the context of homelessness in particular, these methods have an inbuilt tendency to under-quantify numbers and levels of need. With regard to health care, it is essential that "common sense" ways of targeting services are urgently sought (Faculty of Public Health Medicine, 1991).

Evaluating quality

Evaluations of service provision generally give little attention to people who are outside institutional structures. Existing data produced by health authorities fails to measure the extent of low take-up; moreover, it fails to explain *why* services do not reach this group. Estimations of need should clearly take into account the problems homeless people face in gaining initial access to services, as well as aspects of service delivery which act as a deterrent to marginalised groups. Service planners should therefore begin to look more closely at the accessibility, quality and acceptability of current service provision – not only for homeless people, but for all users.

Service specifications, as "statements of DHAs purchasing intentions ... for particular care groups" (NHS Management Executive, 1991), provide an opportunity for improving the quality of service provision. In February 1991 the Medical Campaign Project sent questionnaires to each purchasing authority in London, asking if they had included recommendations for the care of homeless people in their service specifications. Of the ten replies received, three said they

included specifications which related to particular services used by this client group, and only one of these had looked at developing specifications relating to homeless people as a care group. However, four others said that all their specifications do highlight the requirement of equal access to health care and that service provision should be appropriate to the needs of individuals.

As this report has demonstrated, both the organisation and delivery of services and the attitudes of providers present obstacles to marginalised groups, including homeless people. If these barriers are to be overcome, and the opportunities presented by the new legislation are to be maximised, service specifications should identify how this should be done and use this as the basis for contracting. We wish to emphasise that this is a basic equal opportunities issue and is a fundamental prerequisite to ensuring that quality standards are meaningful for all users.

Service evaluation and future developments in provision should ensure equal access to all users. Those who present with multiple medical, social and housing needs should not be excluded from receiving the best possible treatment. There is a real disincentive for individual authorities to improve services for fear of creating overwhelming demand. It is therefore important that this issue is addressed by every health authority to ensure that there is an even distribution of services available to homeless people across London. In the meantime, however, each authority should take responsibility for ensuring that homeless people within their district have access to appropriate and acceptable services.

There is already a wealth of information relating to the health needs of homeless people, much of which makes clear recommendations for improving the quality of services to this group. A further source of information relating to the needs of homeless people is front-line workers in both the statutory and voluntary sectors. Health authorities should make use of both these sources in evaluating need and identifying priorities for action.

Pan-Thames regional initiative

The new pan-Thames regional strategic team which has been set up to develop work on health and homelessness and funded jointly by each of the four Thames health regions and the King's Fund is to be welcomed. It should ensure that a co-ordinated approach to meeting the needs of people who are homeless occurs across London. As the project proposal states:

Part of this work will involve identifying an overall strategic framework for homelessness at regional level through which the region can request locally-negotiated joint strategies between districts, FHSAs and local authorities on homelessness. Part of this strategic framework might be to act as a training resource for encouraging joint training between staff in the districts, FHSAs and local authorities. This will ensure strategic plans submitted by local agencies take on board appropriate services for homeless people and the need to develop appropriate and improved access to services for black and ethnic minority groups.

Joint working

A major aim of the pan-Thames initiative is "to stimulate inter-agency working at a local level". Given the multiple health and social needs which homeless people have, it is vital that good links are developed between all agencies working with homeless people, both statutory and voluntary. This was highlighted at a conference held last year and organised by Camden JCPT homelessness group, when participants overwhelmingly concluded that:

the health needs and housing needs of homeless people cannot be seen in isolation from one another. There is an urgent need for service providers to improve liaison, co-ordination and information sharing to ensure that clients who are homeless receive high quality services which are sensitive to their needs.

As the numbers of homeless people rise, both the statutory and voluntary sectors are having to cope with increasing demands on their services at a time when financial resources are particularly scarce. Lack of co-ordination and communication between the various sectors and agencies working with homeless people means that the services they provide are often fragmented, resources are wasted and needs unmet.

Workers in each sector should be aware of the range of services provided by other agencies (and how to access them) to ensure that existing resources are used effectively. While joint planning involving senior managers is an important component to ensuring continuity of care, there needs to be an emphasis on joint working that pervades throughout each authority and at every level, from senior management to the point of service delivery. It should also be recognised that frontline workers, in both the statutory and voluntary sectors, are a valuable source of information about the needs of the people they work with.

Yet there appears to be a marked reluctance by many statutory authorities to involve the voluntary sector, despite the fact that "it is largely the voluntary sector which is initiating health care work with homeless people ..." (Medical Campaign Project and Bloomsbury CHC, 1989). If services are to become responsive to the needs of users, there must be formal channels of communication between health authorities and community and user groups and a commitment to involving these groups in the planning of services.

Many voluntary organisations have good links within their communities, provide an immediate point of contact, and undertake outreach work to ensure that they reach a wider section of their target population. It could be said that in this way they provide a model of working which statutory authorities should seek to emulate. However the extent to which voluntary agencies can perform these functions is dependent on the amount of resources at their disposal. Therefore we would argue that a well-resourced voluntary sector is vital to ensure the effective accountability of statutory providers.

In relation to homelessness, this means that good links must be developed not only with the established agencies working with homeless people, but also with a wide range of organisations offering

advice and support, and particularly to those working within the black community. There has to be an *equal* partnership between statutory and voluntary agencies and the onus must be on the relevant authorities to listen - and act - on the expertise of frontline staff in all sectors.

Conclusion

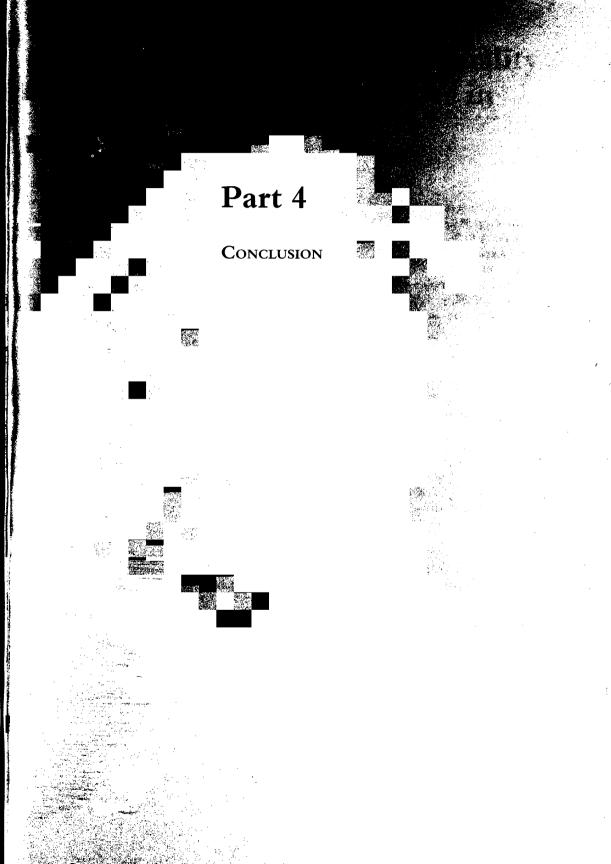
The aim here has been to demonstrate that health policy and the setting of targets and strategies for health must recognise the existence of major inequalities in health and identify ways of overcoming these. This should include tackling the social and economic factors, such as homelessness and poverty, which contribute to so much preventable ill health.

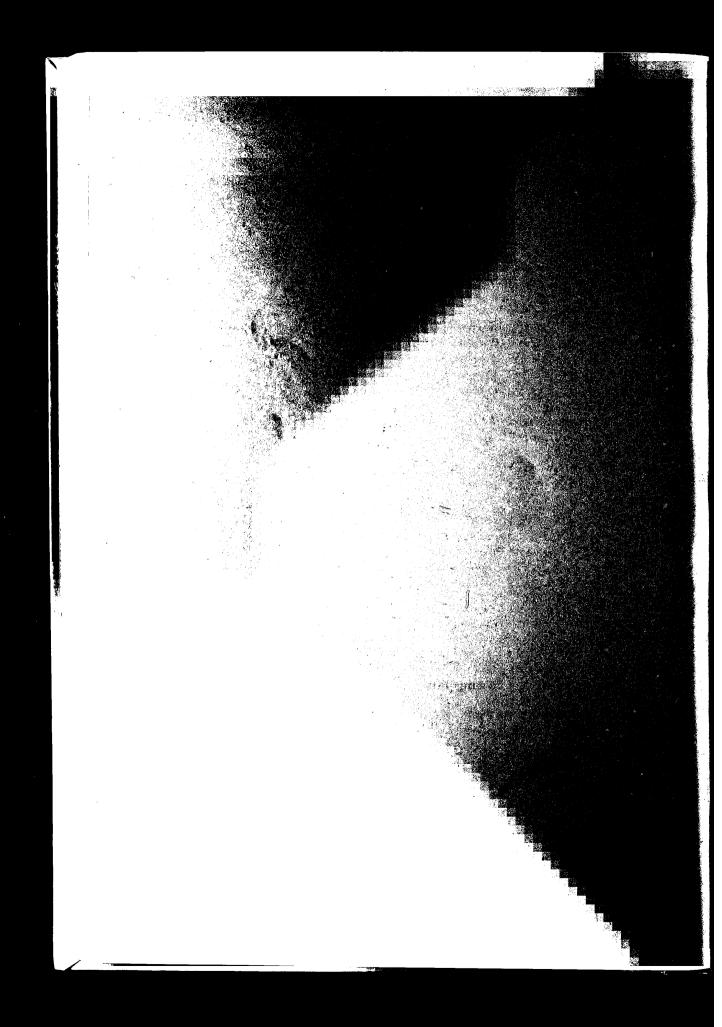
It can be seen that single homeless people face particular difficulties in relation to health care services. Their access to, and use of, acute health services is partly determined by their lack of access to primary care and community health services. The failure of health service providers to recognise their needs or the effect of homelessness on their ability to maintain their health and to keep in contact with health services means that this group is not well-served by the NHS. Single homeless people with mental health problems and those from black and minority ethnic communities are often doubly discriminated against. The conclusion that must be drawn is there is an urgent need to develop a comprehensive and co-ordinated strategy for breaking down the existing barriers which prevent marginalised groups from exercising their right to health care:

Any comprehensive strategy must be concerned both with empowering people to make their own choices (enhancing people's rights) and with ensuring that the services available bring such choices within reach (planning).

(SHIL, 1987)

Throughout this section we have tried to emphasise the heterogeneity of the homeless population. Understanding this diversity is essential for effective planning, since it emphasises the necessity of a comprehensive review of all services in the way that they respond to the needs of single homeless people. Fundamental changes are required to ensure a closer match between health care provision and the needs of users, for example, through greater accessibility and flexibility. Such changes will not only benefit homeless people, but will empower *all users*. The key to effective service delivery therefore lies in developing structures and practices which have the primary aim of empowering users.





CHAPTER



13 Improving the quality of acute services in London

rom this study a number of conclusions can be drawn about the quality of London's acute services. In particular, several important areas need improvement if all Londoners are to receive high quality acute care. Brief notes summarising key recommendations are given below under the six Maxwell headings, as more specific comments about each area have already been made in the text. In order to provide Londoners with high quality acute care into the next century, the following improvements need to be made to the capital's health service.

1 Access to services

The role of GPs

Primary care services in inner London are still relatively poor and need to be significantly improved to enable better access, especially to GPs at night. Policies should be implemented to ensure that everyone is able to easily register with a GP, and FHSAs should disseminate information about the availablity of GPs more effectively. Joint planning between FHSAs and DHAs should be improved. GPs should have more information about the acute services available to their patients and communicate this more effectively to them.

Outpatients

The length of time many people have to wait before attending outpatients clinics is too long: this should be reduced.

Waiting lists

The length of time people have to wait before elective surgery in London is far too long and appears to have significantly increased over the last decade. As a consequence, some services have, in effect, either been greatly reduced or withdrawn. One of the top priorities for improving access to hospital care must be to substantially reduce the time people have to wait before surgery, and to make sure a full range of services is available in each district.

Non-emergency transport

The non-emergency ambulance service has badly deteriorated in recent years, reducing access to hospital for many disabled people. This service needs to be significantly improved to allow anyone who needs the service to get to hospital without delay or cancellation.

Emergency admission

In general the NHS in London provides a high quality service for people in emergencies. However, the response time for emergency ambulances should be reduced to meet government targets.

Rehabilitation and convalescence

The provision of convalescent and rehabilitation services is poor. Services need to be greatly improved to ensure everyone has the chance to make a full and fast recovery.

2 Efficiency and economy

Convenience to patients

In both outpatients and accident and emergency departments, people often have to wait for long periods before seeing a doctor. In addition, a large number of outpatient appointments and admissions for surgery are cancelled. Both of these need to be reduced.

Costs to users

Few direct costs are involved in using acute services. However, the cost of transport to hospital and of appliances can be high and is not adequately met by the Health Benefits Scheme. All essential appliances should be free. Health benefits need to be increased and made easier to claim.

3 Social acceptability

Comfort and ease of use

Many outpatient and accident and emergency departments are uncomfortable, crowded and have few amenities. There also appear to be very significant variations in the quality of inpatient life between different hospitals and wards. A programme to both improve this aspect of hospital care and enforce minimum standards should be introduced. For many people, particularly the elderly, having local services is a most important criterion.

Peoples' social needs

Ensuring social and emotional support for patients is an important and often neglected part of hospital care. Counselling services need to be made much more widely available, giving patients the choice of multilingual and black counsellors where appropriate. Everyone should be carefully assessed when admitted, to make sure they can receive practical help with benefits and with their domestic responsibilities if necessary.

Communication and information

The failure to keep patients informed about their illness and treatment is a major shortcoming. Much greater effort needs to be made to

improve communication with users and to provide comprehensive information in an easily accessible form.

Choice and rights

User's involvement in choices about their treatment is often limited and the basic rights of a number of groups frequently ignored. A comprehensive range of patients' rights should be guaranteed, backed up by a much more efficient system of complaint and redress, and the use of advocacy services for disadvantaged groups. Information about how to make a complaint should be disseminated more widely both to users and those who care for them and act as advocates.

4 Effectiveness

Discharge from hospital

The effectiveness of treatment appears to be increasingly compromised by the occurrence of premature or inappropriate discharge of patients. This causes great inconvenience and increases the likelihood of readmission. Existing policies to improve discharge arrangements must be fully implemented and disseminated to all staff, users and carers. Health professionals need to be made aware of the risks of discharging people to hotels and other temporary accommodation, and to their own homes when they do not have adequate support there. Close monitoring of readmission rates should be introduced.

Clinical standards

At present there is no comprehensive framework for establising, monitoring and improving both clinical and non-clinical standards of care. A programme for setting standards, monitoring adverse clinical outcomes, evaluating new procedures, and enhancing medical audits should be established, involving users at all levels.

Developing measures of outcome and monitoring the impact of change

There is a pressing need to develop meaningful measures of outcomes for all acute services. This would allow a much more useful evaluation of policy and organisational change than is possible at present.

5 Relevance to need

Appropriate services

In a number of important area users have significant differences with staff over how services should best be provided and organised. Groups representing users should therefore be involved in the planning and development of all acute services to make sure their needs are taken into account. There is a particular need to to review accident and emergency services, in order that they may better suit the preference of users and that the need for an emergency psychiatric service is addressed.

Needs assessment

The process of assessing need has an crucial role to play in shaping the future pattern of services. User groups and CHCs should be fully involved in the process of assessing and monitoring needs.

6 Equity

Discrimination

Racism and other forms of discrimination are widespread throughout the acute sector. Highest priority must be given to ending all forms of discrimination and ensuring that everyone will be treated equally. Users who present with multiple medical, social and housing needs should not be excluded from receiving the best possible treatment. A comprehensive equal opportunities programme should be established after widespread consultation with community organisations.

Unequal access to acute services

A number of barriers prevent equal access to services. The lack of multilingual staff and poor physical access to buildings particularly affects black and disabled people. All hospital services should be reviewed and changes made to improve access. All staff training should acknowledge the diverse population who comprise the users of London's health service.

Inequalities in health

Significant differences in health status persist between different classes and social groups. In line with the WHO's Health For All programme, reducing inequalities in health should become the goal of the NHS in London. Health authorities should consider providing more services in areas of greatest health need.

The overall picture revealed in this working paper is of London's NHS under pressure as it tries to cope with a reduction in resources and a range of unplanned cuts in services. In addition, there are a number of long-running issues which have continued to adversely affect hospital services. With the sweeping changes occurring throughout the health service, there is a major opportunity to address these problems.

From vision to action – working towards better acute services in London

Having identified the key areas for improving acute services in London, it is important to look at how these goals might be achieved. Without considering the context and practicalities of implementing change, many policy commitments will remain no more than hollow promises. In order to make this judgement it is valuable to examine briefly how effectively policy have been implemented in the past, and how this might be altered by the new organisation of the NHS.

A number of major themes have run through London health

policies over the last fifteen years, including attempts to:

- shift resources away from the capital and have a planned relative reduction in London's local acute services (the introduction of the RAWP formula, 1975);
- rationalise hospital services and the medical schools (LHPC, 1979);
- expand services for "priority groups" (DHSS, 1981);
- improve the standard of primary care services in inner London (Acheson, 1981).

Of these policy goals, only one has been fairly successfully achieved: the relative shift of resources out of the capital, and out of inner London in particular (DHSS, 1988). This has occurred at a much greater speed than was originally envisaged and has resulted in many unplanned cuts in services across the capital, as health authorities have tried to meet stringent financial targets.

The very high concentration of teaching hospitals and specialist services appears to have had a major impact on both the historic growth of hospital care in London and the way services have been reduced in recent years (Rivett, 1986). There is convincing evidence that the concentration of specialised services seriously distorts the activity of local acute services, with the emergence of "hidden" specialities, where undesignated (and thus not properly funded) specialist provision grows within local acute services (Hogg, 1988). Such "hidden" specialties in London may actually account for one in eight of inpatient cases and a quarter of outpatient cases (DHSS, 1988).

In addition, it appears that the number of beds and outpatient sessions has actually been increasing in some regional specialities in inner London districts, despite heavy cuts in local acute care (Hogg, 1991 forthcoming). Overall the pattern of teaching hospitals and specialist services in the capital has remained essentially unchanged over the last decade, largely unscathed by the dramatic cuts in other hospital services. Few of the moves to rationalise this part of the acute sector, envisaged by the LHPC at the end of the 1970s, have actually occurred (ibid.).

In contrast to the success in reducing acute services, no real progess has been made in realising other major policy objectives. Despite the commitment to priority services contained in *Care in Action* (DHSS, 1981), a study of the provision of services for priority groups in London concluded that there was:

clear evidence that since 1981, or in some cases 1982, there has been a marked downturn in the spending and services devoted to the priority groups throughout London. The decline has been both relative and absolute, that is the priority groups have received less cash and less services, and have lost both faster than the acute services.

(Lipscomb, 1987)

Similarly, following the recommendations of the Acheson Report (1981), few significant improvments have been made to the standard of primary care in inner London, with progress in promoting good

practice occurring at a slower pace than in the rest of the country (Benzeval et al., 1991, p.27).

These failures perhaps reflect a more general shift which has occurred as the number of services regarded as "priorities" has been added to in a piecemeal fashion. In reviewing the growth of high technology medicine in London, Hogg (1988) describes the impact this has had.

In 1976 national priority was given to developing primary care and services for the mentally ill, handicapped and elderly people. However, since 1980, this has changed and priority has been mainly given to new high cost specialist services, often without additional funding. These have inevitably been developed at the expense of other, less heroic, health care. (Ibid. p.3)

It therefore appears that over the last decade few of the major commitments in health service policy for London made in the late 1970s and early 1980s have been realised in practice. Even the reallocation of resources away from London has been made in a different context from that originally foreseen, as general underfunding of the NHS has forced the pace of cuts and closures. It is from the failure to realise these objectives, the planned contraction of local acute services, the improvement of primary care, the expansion of priority services and the rationalisation and tighter control of specialist services, that the crisis in London's acute sector has grown. Any future policy for the capital's health service must address the organisational, managerial and financial inadequacies which have allowed this to occur.

The root of the problem perhaps lies in the inertia which was inherent in the previous system of NHS organisation, planning and management. The corporatist structure of health authorities prior to 1990 institutionalised the power of provider interest groups and mitigated against anything other than piecemeal changes in services.

This was also compounded by the lack of a London-wide perspective, as the capital's health services were divided between the four Thames regions. Co-ordination with other statutory agencies was difficult with the lack of common boundaries between health and local authorties. In addition, Family Practitioner Committees (now Family Health Service Authorities (FHSAs)) had little power to plan primary health care.

The failure of London-wide planning is highlighted in a report by the Inner London Health Authorities;

The key finding is remarkable:

It is not in fact possible to draw a coherent and comprehensive picture of inner London's future health services from the published plans of the four regions, nor indeed from the unpublished documents to which we have had access.

(King's Fund, 1987a)

With the introduction of new organisational and managerial arrangements into the health service, as a result of the 1990 NHS Act, some of these factors have been altered. For the first time since the inception

of the NHS, historic patterns of provision and activity look set to change as a new dynamic is established in the health service. The separation of purchasers from providers could offer new opportunities to change the pattern of care, and help the implementation of long-standing policy goals. However this heavily depends on health authorities taking a strong lead when establishing contracts and paying close attention to the needs of the community. There are severe doubts about whether this will occur, given the merger of authorities, the continuing financial pressure, and their unrepresentative composition.

Although a number of the shortcomings identified previously have been addressed by the reforms, such as an enhanced role for FHSAs, important organisational barriers to improving London's NHS remain. In addition, several potentially devastating processes have been set in train with the introduction of the "internal market". The combination of the move to a population, rather than a historic, basis for funding when combined with the introduction of capital charging is likely to result in a further dramatic decline in the amount of resources available for funding hospital services in inner London.

What is perhaps most worrying about the new arrangements for health care in London is that no-one really knows what impact these radical changes will have. As staff at the King's Fund Institute have concluded when reviewing the future of health and health care in London:

the uncertainties associated with a period of turbulent change could threaten the financial viability of hospitals and other health services in unplanned ways. It is impossible to predict with any degree of certainty what the impact of the new purchasing arrangements will be.

(Benzeval et al., 1991)

It is therefore vital that some coherence and, above all, stability is given to the arrangements for health care in London. In particular, five prerequisites can be identified which would both ensure the management of the radical changes underway and assist the implementation of the improvements identified above.

London-wide strategic planning

A London-wide planning body is urgently required to help coordinate the different purchasing plans which health authorities are currently drawing up. It could also play an important part in untangling the funding and organisation of regional and national specialist services from local acute care. Above all a London-wide authority could take an overview of the capital's health needs and develop a dynamic vision for the future of health care in the city. It is important that any strategic authority is representative of the community, that it involves users and is accountable to the people of London.

Targets and priorities

An important role for London-wide strategic planning would be to establish clear targets and priorities for health care. As outlined above, strategy could be developed from the government's endorsement of the WHO's Health For All programme, with the pursuit of equity in health and health care as a primary objective. It would be important for practical targets focusing on health outcomes to be established, allowing close monitoring and evaluation. A model along these lines is already being developed for the NHS in Wales. The Welsh Health Planning Forum has drawn up a clear strategy for the future of health in the principality, setting out a number of priority areas which focus on maximising health gain (Welsh Health Planning Forum, 1989). There is no reason why this example cannot be applied to London, building on and developing the targets and commitments set out in the Government's Green Paper *The Health of the Nation* (HMSO, 1991).

Co-ordination and integration

In order to prevent the further fragmentation of services and ensure a close integration of primary, secondary and social care, improved coordination between health authorities, local authorities and FHSAs should be introduced. The best way of helping this process would be to make sure either that boundaries between health and local authorities were coterminous or that health authorities covered several London boroughs. Local authorities could be closely involved in both the process of needs assessment and contracting for services, to provide co-ordination with social care services.

Mechanism for ensuring quality

A powerful system for monitoring and ensuring the many aspects of the quality of hospital services highlighted in this working paper should be established. The principle of independent review should be central to assuring quality. Any programme would, therefore, have to remain separate from both purchasing authorities and provider units. It would also be essential to heavily involve both voluntary organisations and user groups in this process. CHCs also have an important role to play in a system of quality assurance.

Extra resources

With the continued underfunding of the NHS, the planned contraction of acute services in inner London, and the likely impact of the workings of the internal market, the pressure on London health authorities' financial resources seems likely to further intensify. This should come as no surprise, as implicit in the shift to population-based funding and the introduction of capital charging is a policy for the rapid geographical reallocation of health care resources away from London. As a consequence it appears inevitable that a major financial crisis faces London's health services in the very near future.

To aim to enhance the quality of acute services against a background of a rapid reduction in resources and major structural change is an illusion, as many of the improvements needed would require long-term stability and additional resources.

If London is in any way a special case it is because the scale of the changes in its health services now in train are so much greater than in any other part of the country. This must be recognised, by giving

London health authorities additional resources above their population-based allocation, to enable them to cope with the major readjustments inherent in the reforms. This "transitional" relief could be slowly phased out.

Without mechanisms for strategic planning, ensuring the integration of services, and additional funding to cope with the current crisis facing London's NHS, the quality of acute services for Londoners is certain to deteriorate.

APPENDIX 1: THE SYMPOSIA

Method

From the outset of the GLACHC work on user perspectives of London's acute services, it was recognised that the direct participation of users was essential in order to supplement the material that was generated from a diversity of sources including questionnaires, letters, interviews and a review of material from CHCs. It was decided that this user participation should be facilitated by a series of symposia.

Four symposia were convened, each lasting for a half-day or slightly longer. The topics for the symposia were chosen to reflect the main areas of interest in the research where it seemed that direct user experience could add insight and illustration to the other information collected.

Two symposia directly mirrored the topics examined in Parts 2 and 3 of this working paper: one was held on single homelessness and access to acute health services, and one on acute services for elderly people. The symposium on the experiences of single homeless people was a relatively small meeting of people who had attended a large conference on the subject, at which there had been wide user involvement as well as good participation from professional workers in the field. It was felt that it was unrealistic to convene a full symposium so soon after the conference, and it was preferable to distil the views of this in a smaller meeting.

The symposium on elderly peoples' experiences of acute services, in contrast, consisted mainly of elderly people who were actual and potential users of the services in question. Not surprisingly, there was an overwhelming amount of valuable evidence from this symposium. In order to get the most out of this symposium, it was quite tightly structured and discussion was organised under relevant headings in order to cover many aspects of the situation.

A third symposium was held to discuss discharge policies and practice. It was attended by a wide variety of people from CHCs, voluntary organisations and some interested individuals. Inevitably, there was some overlap with the elderly persons' symposium in terms of subject matter and the nature of the anecdotes and experiences, but in addition useful evidence was gathered about the impact of discharge policies on children and the whole age-range of patients.

The fourth symposium was somewhat different, as it was convened in order to provide an opportunity for black people to speak freely about their experiences as users, or potential users, acute services in London. This was, therefore, restricted to black participants in order that they could share experiences in a safe and sensitive environment.

It is important to note that all the symposia took issues of race and culture very seriously, in terms of both the content of the discussion and who was invited to attend. In fact the other symposia, particularly the one on elderly people, were well attended by black and minority ethnic people, and

the purpose of having a symposium for black people to discuss their perceptions was to supplement the many useful points that were made in other meetings.

The symposium for black and minority ethnic people was organised and facilitated by the Black Community Care Alliance and the National Community Health Resource.

A very wide range of organisations were invited to take part in the symposia, and the invitation to attend was supplemented by a short discussion paper, which served as a launch pad for initial discussion. The meetings were chaired in order to ensure the widest possible participation from users, and the discussion was structured to a certain extent in order that the relatively short time available was used to examine diverse aspects of acute services. Special encouragement was given to enable participants to indicate examples of existing good practice as well as recounting some truly horrific examples of bad practice.

It was notable that the participants had great awareness about the problems of running good, sensitive services. In fact, realism, bordering on low expectations, was more common than utopianism.

No charge was made for attendance at the symposia and there was a great deal of commitment shown in the high attendance, the willingness to travel into central London for the event, and the high level of debate.

The only reward sought by participants was that their views should be faithfully and fully integrated into the research report and that ultimately these views would influence members of the King's Fund Commission in its deliberations on the acute services for London in the future.

Summary of main points from symposium on single homeless people and access to acute health care: Friday, April 5th 1991

Problems with acute services

Attitudes

• Staff working in hospitals often seemed to have little awareness of the particular local circumstances and issues that their patients faced.

Policy and organisation

- People were often discharged from accident and emergency departments with nowhere to go and there was usually no requirement to take details of a person's circumstances and check that he or she had somewhere to stay that night;
- There was considerable discussion about the lack of information available/ accessible to staff working in hospitals about resources such as hostels and transport;
- Much more attention needed to be paid to the dissemination of discharge
 policies. One person said that "the person drawing up the policy is miles
 away from the person who is supposed to empty the bed". This could be
 done through guidelines on policy implementation.

Structural issues

 Concern was expressed that homeless people would suffer in the new contracting system as the provider will not be able to bill a purchaser for people who don't have an address.

Ways to improve services

Attitudes

- It was felt that changes in attitudes had to be effected at a senior level; for example amongst consultants;
- One way of doing this was through training. It was pointed out that frontline staff and management had different training needs.

Policy and organisation

- There was discussion about the role of social workers and social work teams in accident and emergency departments and the desirability of a nurse practitioner being employed there;
- It was suggested that there might be a co-ordinating centre open twentyfour hours that could provide information to workers in accident and
 emergency departments. This could use one of the existing agencies. It was
 also felt that those that did exist could be better publicised; for example,
 hospital social work departments should have a copy of the hostels
 directory;
- It was felt that there should be some input into accident and emergency special nurse training courses on accessing information;
- It was noted that those health authorities which had good paper policies were either those which employed workers or advocates for the homeless (e.g. Tower Hamlets and Bloomsbury) or where the officer who had drawn up the contract had a particular interest in the issue (Riverside);
- It was felt that there should be someone with clear responsibility for policy on single homeless at both Regional and District Health Authority levels;
- For the successful implementation of policies it was felt that there needed to be citizen advocates to uphold them and take up individual cases;
- It was also felt that a summary of discharge policy guidelines should be displayed for the public.

Structural issue

- It was stressed that at the end of the day there should be more resources available to keep people in hospital until there were suitable arrangements made elsewhere:
- It was felt that there needed to be more liaison at government department level, for example between the Departments of Health and Environment;
- There was also discussion of the need for both convalescent facilities and also after-care support (particularly for people with mental health problems).

Summary of main points from symposium on acute care for elderly people: Tuesday, March 5th 1991

Access to services

- Levels of some services such as cataract operations and joint replacements are less in London than elsewhere;
- There may be a circle of low expectations which lead to low levels of service provision, which, in turn, lead to further low expectations;

- Long waits for treatment and admission were often made worse by repeated cancellations, sometimes at the last minute;
- Systems for referring people to hospital were too slow;
- Transport to hospital was extremely difficult. There were not enough ambulances, and journeys were frequently cancelled;
- Generally, a preference was expressed for treatment close to home. There
 was a fear that the internal market might lead to treatment at more distant
 hospitals if they were cheaper. This fear was particularly expressed in
 relation to fundholding GPs;
- Shortages of occupational therapists led to problems in accessing necessary services;
- Shortages of social workers had a similar effect;
- There was inadequate information available to patients and carers about the services and benefits that were available;
- Communication needs to be improved. Information should be free from jargon and available in community languages in order to improve access to relevant services;
- · Access to respite care was not adequate;
- There was a perceived need for more convalescence facilities.

Relevance to community needs

- Closure of specialist beds for elderly people led to the admission of elderly people into general medical and surgical beds, with a knock-on effect on admission to those wards;
- A relative lack of nursing home accommodation in London led to people having to go all over the south-east of England for care;
- Good social work or discharge teams might provide a route to services after an acute admission for those people who gained access to services through them, but in the absence of adequate resources, this might mean that there was little capacity to meet the needs of other people;
- Lack of resources in many aspects of health and social services were identified;
- · The needs of carers were not always taken into account.

Effectiveness for the individual

- There was considerable stress associated with long waiting times for admission:
- Mis-diagnosis sometimes occurred in elderly people on emergency admission to hospital, when the consequences could be disastrous;
- Staff were not always able to cope with dementia in a patient having medical or surgical treatment;
- There was a significant problem associated with the loss of dentures and glasses of elderly people while in hospital;
- Both admission and discharge should be carefully planned;

- Early discharge represented a problem for nurses as well as patients, as there was a faster throughput of patients, who were always at the acute illness stage and not in a recovery period;
- Delays in starting community services after acute illness posed great problems for elderly people;
- The effectiveness of home care after acute illness was limited by the increasing professionalisation of home-help services, which sometimes created difficulties in obtaining routine domestic and cleaning services.

Equity

- NHS and private hospitals appeared to use different criteria for treatment.
 For example a cataract judged unready for operation in the NHS was dealt with immediately in the private sector;
- A number of cases were cited where people had opted for private care in desperation, when they could not really afford to do so;
- There were problems in linking into statutory community services after such private treatment;
- Ageism was common and inappropriate assumptions were often made about elderly people. Two unwelcome phrases: "it's your age" and "too old to treat" were encountered quite often;
- Quality Adjusted Life Years (QUALYs) were seen as inadequate tools when applied to elderly people;
- There were fears that elderly people were denied expensive medicines due to cost;
- The special needs of many elderly people, such as the need for large, clear print, were not fully acknowledged;
- Interpreting and advocacy services were grossly inadequate.

Social acceptability

- The discrepancy between professional and lay opinion on the benefits of specialised wards for elderly people was recognised;
- Geriatric wards were widely feared, as were bullying and mistreatment;
- However, it was recognised that there was a dilution of expertise associated
 with a policy of dispersing elderly patients across a large number of wards.
 The difficulties of implementing discharge policies in such circumstances
 were also noted;
- Some elderly people prefer to be nursed by mature people, although the
 progressive influence of some young geriatricians in the past two decades
 was recognised;
- The quality of food and the quality of help available to elderly people who
 require help to eat were both criticised;
- There were some fears of being kept alive for longer than the individual wishes to be treated;
- · Improved care should be available for people who are dying.

Efficiency

• Value for money is a wider issue than simply looking at a health authority's

budget. The cost of users' and carers' time is also significant. Travel costs should also be considered;

- Emotional stress caused by delayed or inappropriate treatment also has a significant cost;
- The use of "home finders" to "unblock beds" was viewed with some suspicion as it was not clear in whose interests they were employed.

Summary of main points from symposium on discharge from hospital: Monday, April 8th 1991

Early/inappropriate discharge

- One CHC had a problem in obtaining detailed discharge procedures;
- In many cases, the situation was good in theory but poor in practice as
 policies were not implemented. Even detailed case conference decisions
 were sometimes overlooked;
- Where good policies existed, individual needs must be taken into account in implementing policy;
- Elderly people, in particular, were thought to be discharged too early and to have difficulty in securing re-admission;
- Discharge problems were linked in some cases to "bed-blocking";
- There was overwhelming support from many participants for the need for convalescent facilities and "half-way" care for people recovering from acute illness;
- Early discharge for children was supported. However, long waits to see a
 doctor before discharge could lead to children going home very late at
 night. Also, both pain relief and community paediatric services were felt
 to be inadequate. The impact of childrens' early discharge on parents needs
 to be understood:
- Both lack of funds and poor management were implicated in poorly planned discharges;
- There was a small minority in support of the view that the solution to discharge problems is to keep people in hospital for longer periods;
- Examples of good practice included a team approach to discharge and a commitment to planning discharge from the date of admission or earlier. The use of volunteers to help with practical tasks on discharge provoked a mixed reception; some supported it and others saw it as inappropriate.

Involvement of users

- The concept of user involvement implies choice. However, this is not always available, for example women often have very early discharge after childbirth, whether they wish to or not;
- Some psychogeriatricians were prepared to talk to users but not to primary carers:
- Services were sometimes discontinued without prior consultation with the user.
- There was a perceived lack of a complaints procedure within the system.

Social factors

- Sometimes, no enquiries were made into a patient's home circumstances. This could lead to patients being sent back to problems such as harassment from a landlord. In extreme circumstances, a potentially suicidal man was discharged from acute care without anyone knowing how he felt;
- Children of homeless families were often discharged to unsuitable accommodation; there were insufficient health visitors to care for them;
- There should be improved support for parents to care for children after discharge, including leave from work for the purpose;
- There was some limited support for discharge placement officers to be employed in the hospital. More participants supported the idea of hospitalbased social workers performing their tasks, as discharge officers were seen simply as bed-clearers;
- Many problems were highlighted in the performance of social workers and other social services staff. Shortages of social workers were common and many patients do not see a social worker;
- There are growing problems as to who should pay for the social work service in hospital, particularly where patients are not in their own local authority area.

Communication

- Problems in communication between NHS staff and social services staff
 were very common. Health service staff frequently do not understand the
 organisation of social services departments. Communication with other
 outside agencies was also poor;
- Hospital staff often promised the patient social services, then neglected to tell social services what they had promised;
- Communication about what is available in the community was poor; for example, information on benefits, lists of self-help groups are needed;
- There was an apparent lack of resources, including clerical resources, which hampered communication;
- Communication with GPs was poor and led to problems on discharge, especially after treatment in accident and emergency departments;
- Homeless people were often discharged to unsuitable accommodation.
 Prior communication from the hospital makes a difference. This works best where a liaison network is set up, though the onus falls mostly on voluntary organisations;
- · Inadequate information was given to patients on discharge;
- Examples were given of good practice. These included the use of key
 workers, especially for improving communication with and about children. For adults and children, the collation of information from admission
 onwards was felt to contribute to better communication around discharge.
 In one case, an accident and emergency department had analysed all its
 incoming phone calls, and this had led to rewriting the information
 communicated to patients.

Discharge from/to private care

· Patients who were admitted for acute treatment were sometimes pressu-

rised into going into private residential care;

- Private treatment could cause queue-jumping where treatment began in a private hospital but continues within the NHS;
- People leaving private hospitals found it hard to link into community services and could not afford further private care.

Transport

- Shortages of staff and vehicles in the ambulance service were identified as key problems, but some felt that bad management was also significant;
- There was both support and opposition expressed on the use of voluntary drivers;
- Many people feared the impact of new contracts in the NHS on the situation of patients' travel and transport. Longer distances might be involved for some specialities. GP budget holders might refer patients to distant hospitals for acute treatment if waiting times or other conditions seemed more favourable and this had implications for transport;
- Many people had first-hand experience of delays and cancellations of ambulances. Transport home after a hospital stay was a particular problem.
- Transport to regional centres was a problem. Children and carers often had to make their own way back from such centres;
- Very early or very late journeys caused particular problems, especially for children. It was felt that overnight stays might sometimes be preferable;
- Too much was expected of families in getting people to hospital.
 Expectations of the extended families of minority ethnic patients were particularly unrealistic;
- Voluntary organisations were receiving increasing and inappropriate requests to assist with transport to and from hospital.

Summary of main points from symposium on black people and acute services: Friday, April 19th 1991

Problems with acute services

Knowledge of services

People do not understand the structure of the NHS. This makes it difficult
for people to get access to services and for them to judge the standard of
the service that they receive. Choices are not offered to users.

Language barriers

- There is a great lack of trained interpreters/advocates at the places where people go in crisis;
- Even where interpreters are employed they are not able to change the services to make them more appropriate;
- People feel isolated and alienated by the use of jargon.

Doctors

 Black peoples' experiences lead them to mistrust the medical profession – to the detriment of their health;

- GPs were often dismissive about black peoples' health problems and were reluctant to refer them to specialists. There were also complaints of late diagnosis;
- Consultants did not explain things to patients and made assumptions about black peoples' illnesses.

Culture

- Global assumptions are made about people from particular cultures and about their ailments:
- There should be a recognition of peoples' individual needs. This should take into account the cultural dimensions of behaviour and actions, but not make assumptions about them;
- Black people who know their rights and insist on services are seen as aggressive. One participant commented that "assertion does not seem to be acceptable from black people".

Discharge/community services

- People are discharged far too early. False assumptions are made about the support available from extended families. Aftercare services seem almost non-existent. Health and social care workers in the community are not trained to understand different cultural needs and attitudes;
- One comment from the seminar was that "white professionals should be trained on how to treat people they do not like; race awareness only confirms their prejudice".

Health and black communities

- Other issues often take priority over health for black communities even though they are linked and have a detrimental effect on health. Such issues as immigration, employment, housing, housing and education usually take priority. There is, therefore, a need to raise awareness and mobilise black communities around health;
- Conditions that disproportionately affect black people, such as sickle cell, are given low priority within the health service. Sicklers often have contact with the acute services through accident and emergency departments to inpatient episodes.

Racism

- Hospitals are often frightening and hostile to black people; "you are putting your life in the hands of people who do not like or understand you";
- Racist implications in service delivery are not always clear. This makes it difficult to make a specific complaint.

Ways to improve services

Black people within the health field

- Services would improve if there were more black people at higher levels
 in the NHS. Interview panels should include black people. There needs
 to be more equal opportunities workers and monitoring of employment
 practices. Black workers need more support;
- The contribution that black people make to the health service, both as workers and taxpayers ought to be recognised by the delivery of appropriate services;

- Black organisations should be used in the better co-ordination of aftercare services. These organisations should be supported through funding and given access to expertise;
- Black users need more advocacy provision. Black counsellors should be available whenever they are needed in places such as accident and emergency departments.

Education and training

- Medical training is based on western knowledge. This should be more
 universal in its outlook. For instance, the acceptance of referrals from
 natural therapists. Medical training is insensitive and Eurocentric. It could
 be made more culturally diverse and centred on people rather than being
 mechanical;
- Health workers should engage in on-going training that recognises black people as an equal part of the population;
- Black communities need information and education about the services that are available. This information should be in appropriate languages and formats. Once black people have this information they are better able to lobby and campaign for appropriate services.

Future services

- The new contracting system should be used to provide appropriate services. Where existing services are failing, contracting should be used to improve the type of services offered. More specific, innovative services are needed for black people;
- There should be a shift towards preventative services;
- There should be continuity of care between the different sectors;
- Health should be viewed more holistically;
- Health care should be a partnership between professionals and patients;
- Black users should also be involved in health policy and allowed to define their own needs;
- Health service planners should consult more with communities and implement findings;
- Resources to support black health service user forums should be identified, in order that black people can contribute effectively to policy making.

APPENDIX 2: PARTICIPATING ORGANISATIONS

Organisations which provided information for the GLACHC study of London's acute services

Association for Victims of Medical Accidents (AVMA)

Alzheimers Disease Society

Association for Improvements in Maternity Services

Cancerlink

Chest, Heart & Stroke Association

College of Health

Consumers for Ethics in Research

Family Planning Association

Health Rights

MIND

National Association for the Welfare of Children in Hospital

National Association of Leagues of Hospital Friends

National Asthma Campaign

National Federation of Kidney Patients Associations

NCVO - community care project

Royal National Institute for the Blind

SENSE

Spinal Injuries Association

United Kingdom Thalassaemia Society

In addition information was received from a large number of Community Health Councils.

Organisations which provided information for Part 3: "Acute care for single homeless people"

Alone in London

Arlington House (Positive Health Worker)

Bondway Night Shelter

Brent & Harrow FHSA

Carrington House Hostel (nurse)

Centrepoint hostel for young people

Compass Project

Fanon Project

Forward Project

Haringey Irish Community Care Centre

HHELP

Kings Cross Homelessness Project

Lambeth Link

Links Club

Lewisham Mental Health Users Forum

Primary Care for Homeless People (PCHP)

Simon Community

St Mungos

South East London Consortium

Southwark Day Centre

Spur House Hostel

Threshold Housing Advice Centre

West London Day Centre

In addition other information was received from individuals in a personal capacity.

The symposium on health care for elderly people

Organisations participating included:

Age Concern, Bexley

Age Concern, Lewisham

Anand Mandal Asian Elderly Group, Islington

Anchor Housing, Hackney

Barnet Elderly Asians Group

Bexley Council for Racial Equality

Bloomsbury CHC

Camden Chinese Community Centre

Croydon CHC

Ealing CHC

Enfield CHC

Guyanese Organisation for Cultural Advancement

Hampstead CHC

Middlesex Hospital, Social Work Department

Milap Day Centre, Southall

Newham CHC

Parkside CHC

Pensioners Link, Camden

Pensioners Link, Hackney

Riverside CHC

Tower Hamlets CHC

Waltham Forest CHC

In addition there were a number of individuals attending in a personal capacity.

The discharge symposium

Organisations participating included:

Age Concern, Brent

Age Concern, Greater LOndon

Barnet CHC

Bexley CHC

Bromley CHC

Croydon CHC

Ealing CHC

Enfield CHC

Hampstead CHC

Haringey CHC

Hillingdon CHC

A USER PERSPECTIVE

Lambeth Link
League of Jewish Women (Barnet)
Lewisham & North Southwark CHC
Medical Campaign Project
National Childbirth Trust
National Association for the Welfare of Children in Hospital
Newham CHC
Westminster Forum for Senior Residents
Wandsworth CHC

In addition there were a number of individuals attending in a personal capacity.

The symposium on black people's experiences of acute services

Organigations attending included:

African Caribbean Community Development Unit Bexley Council for Racial Equality
Black Health Forum
Black Community Care Alliance
Fitzrovia Neighbourhood Centre
Glyndon Health Project
Haringey CHC
London Black Women's Health Action Project
National Schizophrenia Fellowship
Newham CHC
Sickle Cell Anaemia Research Foundation
Waltham Forest CHC
Waltham Forest West Indian Association

In addition there was a large number of individuals attending in a personal capacity.

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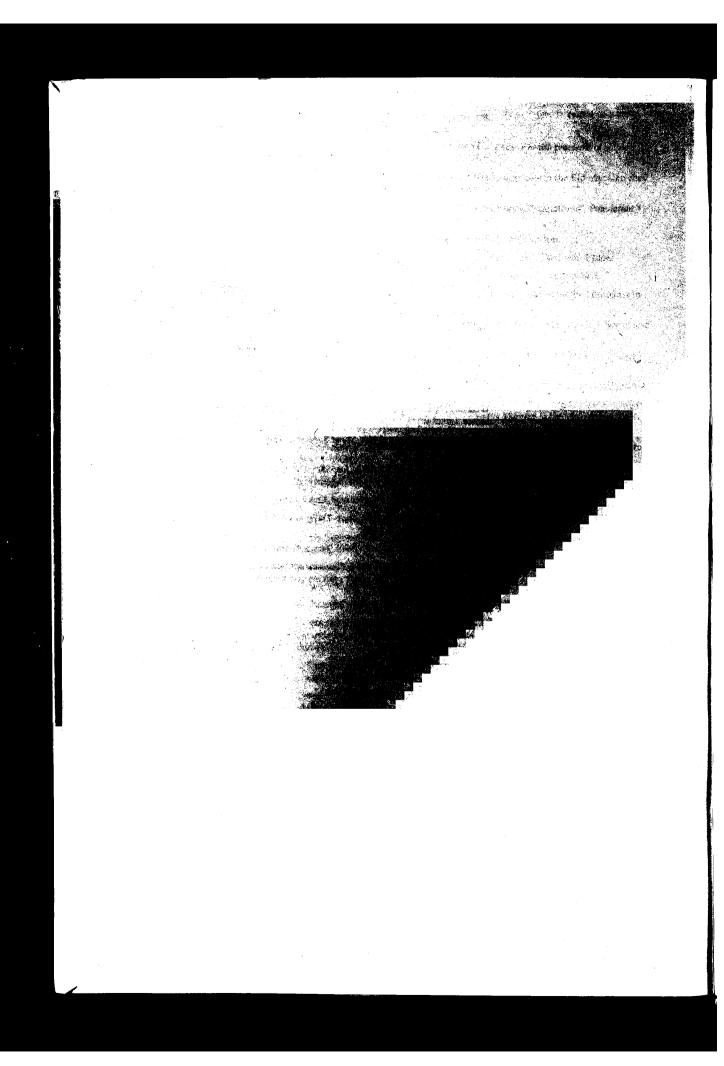
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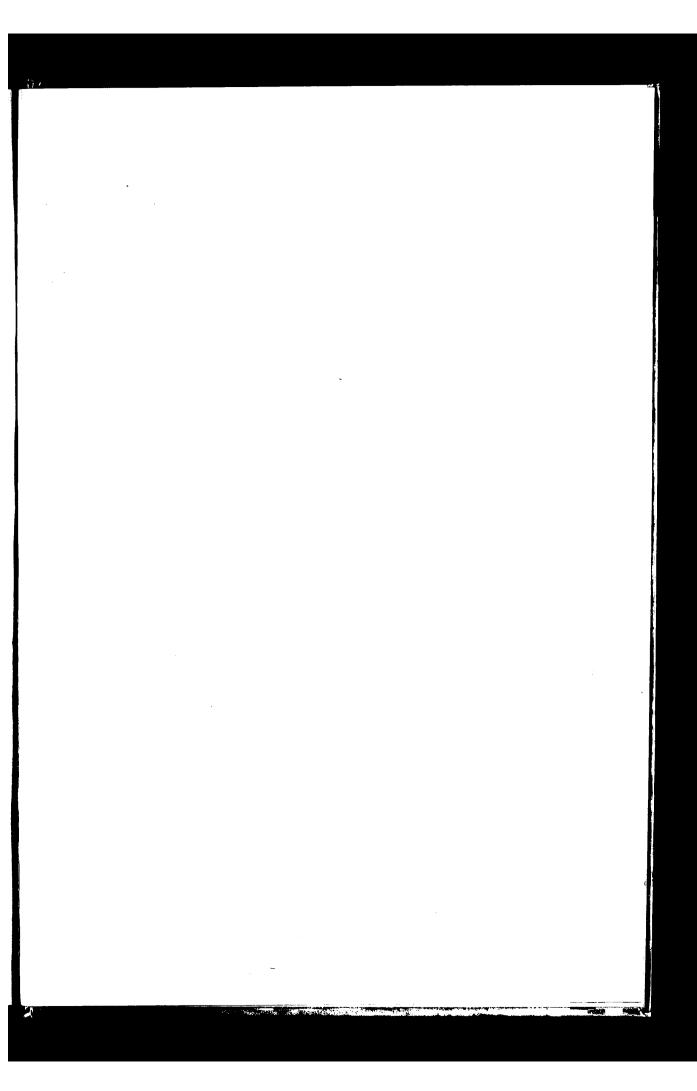
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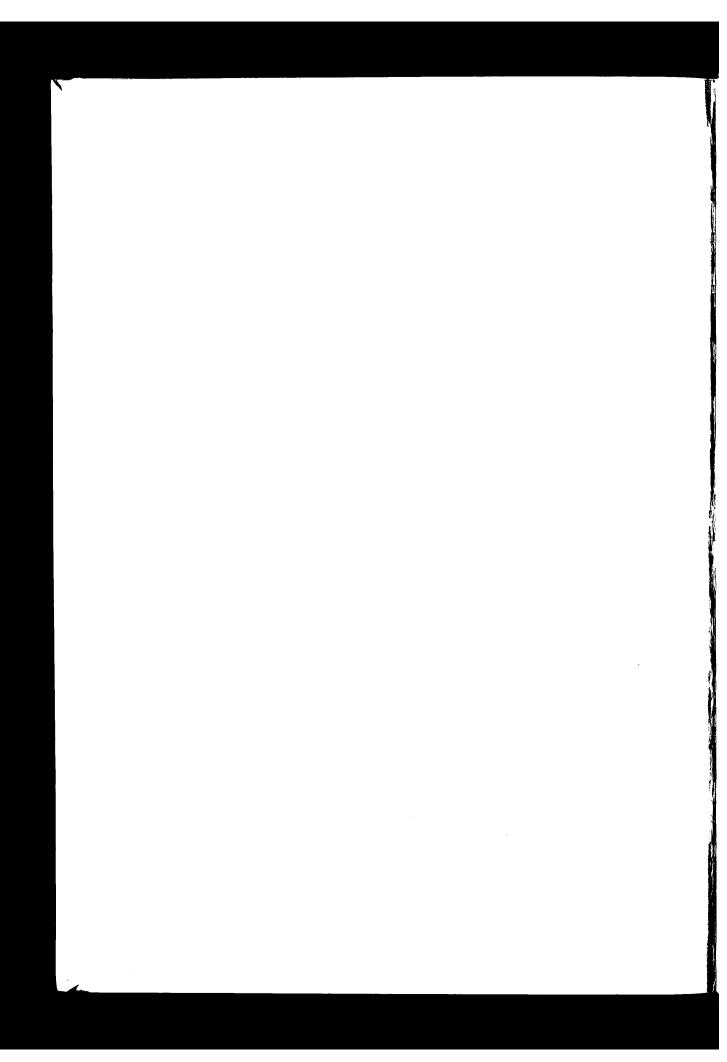
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KING'S FUND LONDON INITIATIVE WORKING PAPER NO. 6

A User Perspective: Views on London's acute health services was prepared to inform the work of the King's Fund Commission on the Future of Acute Services in London. It is being published in advance of the Commission's strategy for London in order to inform debate about the future of health care in the capital. This paper should not, however, be interpreted as in any way anticipating the recommendations of the Commission's final report.

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The King's Fund Commission on the Future of London's Acute Health Services' terms of reference require it to "develop a broad vision of the pattern of acute services that would make sense for London in the coming decade and the early years of the next century". With this in mind, the Fund's London Acute Services Initiative has undertaken a wide-ranging programme of research and information gathering on the Commission's behalf, of which this working paper represents one part.