user friendly services

GUIDELINES FOR MANAGERS OF COMMUNITY HEALTH SERVICES

Liz Winn
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KING's FUND CENTRE

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KING'S FUND CENTRE FOR HEALTH SERVICES DEVELOPMENT

PRIMARY HEALTH CARE GROUP

King's Fund Centre for Health Services Development, 126 Albert Street, London NW1 7NF

CONTENTS

Section 1

INTRODUCTION

This book has been written to help managers of community health services make their services 'user-friendly', and to ensure that the user's point-of-view is taken into account. By users we mean not only current patients or clients, but those who may at some point use services, or care for someone who does, or have a friend or relative who does.

We have written the book with managers in mind because efforts to make services more responsive to users need to be properly supported and resourced. We see the development of user-centred services as a major management task: it is managers who shape the organisational environment, support staff, allocate resources and establish commitment.

We hope that our readers will include community unit managers, locality managers, neighbourhood nursing team managers, and others who want to make services more responsive to users. Of course, managers are not the only group with this interest: voluntary organisations, field staff, user groups and community health councils may all be engaged in promoting user involvement, and we hope they too will find this document useful.

One of the main functions of this book is to display the range of approaches which have already been developed, but not simply so that ideas can be transplanted - even if that were always a good idea. Looking at what has been tried by others can also help to avoid some of the pitfalls and maximise the chances of success. It also draws attention to what exactly is involved in embarking on work of this kind.

Six case studies are included together with a number of less detailed examples. They do not necessarily represent good or bad practice, but each illustrates a number of practical lessons for managers who want to attempt something similar.

We gathered information about case studies by talking to key people and/or by drawing on detailed written material. The interpretation and analysis of the case studies, though sometimes guided by interviewees, are our personal views and do not necessarily reflect the perceptions of the people we spoke to.

We hope also that the book will help managers to get beyond the fashionable rhetoric of health services 'consumerism'. Lurking beneath such rhetoric and a smattering of surveys, suggestion boxes and poorly attended public meetings are the worries of many managers that the game's not worth the candle - that considerable time and effort will be put into an exercise that at the end of the day will produce a number of headaches, unrealistic demands, not much that is useful, and an unchanged service.

At the same time, it is difficult for managers to dismiss the issue of user involvement in services: pressure from central government and health authorities consistently contrive to place the matter firmly on the management agenda. Besides the pressures from above, many managers recognise in principle that developing user-responsive services could be a way of improving the quality of services, or shifting the power balances between managers, professionals and users, or allowing people to exercise rights to determine their own health care. We hope that this book adds to the debate already taking place about why this is important and how it can be done well.

STRUCTURE OF THIS BOOK

Section 2 sets the context for NHS consumerism, describes the background and ideologies and explains its language. Section 3 discusses the importance of being clear about the aims of any initiative and explicit about the style to be adopted. Section 4 then looks at the groundwork and preparation needed within the NHS itself, and Section 5 at the same within the community. These two sections form a discussion on 'getting the environment right' as a background to the detailed implementation of any particular programme.

Section 6 is a brief look, and to some extent a debunking, of what is undoubtedly the most popular and fastest growing aspect of NHS 'consumerism' - surveys. In Section 7 we discuss some other options. Completing the book is a brief guide to further reading and useful contacts.

WHY THIS IS IMPORTANT FOR MANAGERS

There's no doubt that the complexities and practical problems of making services more responsive to users are daunting. We want to highlight some of the very good reasons for setting off across this political and managerial minefield.

Efficiency

Providing services which are inappropriate, unacceptable or inaccessible is wasteful. Badly attended clinics have high overheads. There is also a high opportunity cost since an underused service can drain resources away from a more imaginative and responsive service.

A greater awareness of user views will help managers to understand whether service underuse is due to the service being inappropriate, an off-putting delivery, inconvenient opening times or 'simply' a lack of information. In other words, finding out why a service is underused will help managers make decisions about how best to use their resources.

Reducing inequalities

The law of 'inverse care', that services are most easily available to those who need them least, has long been recognised in the NHS (1), and yet still proves difficult to counter. It is clear that health services are failing to meet the needs of the most disadvantaged (2,3). One way of making sure that services are better geared towards all groups in the community is to foster and support user involvement in the planning and providing of health services. On pages 53 and 36 we describe two attempts to do this - local advisory groups in Lambeth and the Haringey black and ethnic minority worker.

Recruitment and retention

When effort is made to gear services towards the needs of users, job satisfaction among staff tends to increase. In some cases this is because the *mechanics* of gathering user views add an extra, interesting dimension to the normal workload, for instance, health visitors involved in group discussions, planners leaving head office and visiting local organisations, managers sitting in waiting rooms and talking to patients. More important, job satisfaction is enhanced when staff feel that the service they provide is recognised by its users as being valuable and good to use. It then becomes much easier to recruit and retain staff, as the service becomes the focus of attention and a centre of excellence (4,5).

Impetus for change

Managing change in the NHS is notoriously conflict-ridden and slow. User involvement has the potential for simplifying the process, since clear messages from users about what is wrong with existing services are embarrassing to ignore and can provide a useful lever for reshaping services.

Appropriateness

It is difficult (if not impossible) to judge whether or not a service is appropriate for people using it unless their views and ideas are incorporated. There are lots of things that users know about services (that the ante-natal clinic, for example, runs in the school closing time) that tend to by-pass managers, and even field staff. And there are often some inaccurate assumptions made about what 'they' want. The Mildmay Mission, for instance, which is a hospice for people with AIDS, referred to 'partners' of dying gay men. In fact, after having spoken to patients, the staff found the term 'lovers' was preferred. Sometimes misunderstandings may stem from stereotyped views about other groups in the community, such as assuming that all Asians are vegetarians. From a manager's point of view, users are a valuable resource and information bank that should be exploited.

Community health services

The above arguments are particularly relevant and powerful in community health services. In some ways attempts to involve users in community health services generate problems that do not arise when changes to hospital practice are planned - such as dispersal of staff, difficulty of evaluation, number of professions involved. On the other hand, they often deal with local people who have a long term involvement on a regular basis allowing personal relationships to build up, and in many cases the quality of the non-clinical aspects of the service is a very large part of determining the overall quality of service. There therefore seems to be great potential for improving the way in which services are delivered to users, even before tackling any need for changes in clinical and professional practice.

Of course, not all of the advantages mentioned above are going to be apparent in every initiative taken to try and improve services for users. On the other hand, the combination of one or two of them may contribute to a qualitative improvement in the provision of services -

and should also mean that the service is better managed overall.

To put this in context, a look at a practical example may help to illustrate the types of changes that are possible. The following case study of the Lambeth Community Care Centre is not used here to portray a service that is good in all respects, rather to highlight some of the practical advantages for both users and staff of trying to place service users centre stage.

CASE STUDY: *Lambeth Community Care Centre*

Lambeth Community Care Centre is a small, community-based GP hospital with 20 in-patient beds and a day unit for 35-50 patients. It also has facilities for out-patient treatment and meeting rooms open to the local community. In-patient or day patient admission is via those local GPs who choose to become involved with the centre and abide by its rules.

Clinical responsibility remains with the GP (24 hour cover must be provided by the GP's practice or a named deputy) but care is planned and carried out on a multidisciplinary basis and co-ordinated by a key worker, who also has responsibility for maintaining any existing connections with primary health care workers or local authority staff.

In its history and current functioning the centre illustrates several different forms of user involvement. It is the result of ten years hard work. In 1975 the then area health authority stated its intention to close Lambeth Hospital. It began the consultation procedures required for such a closure. To its surprise, the local community health council did not immediately oppose the closure. Instead it launched a large-scale consultation into what sort of facility was needed, involving public meetings, a household survey, discussions with local community health staff, GPs, home helps, tenants' associations and voluntary organisations.

The result was demand for a small, local neighbourhood hospital, providing rehabilitation and intermediate care for local patients. Working very closely with members of the authority, a group of local enthusiasts centred round the CHC and a few GPs developed proposals and campaigned for five years until funding for the centre was eventually approved.

The group which had played such a vital part in the development of the brief was keen to remain involved, and as a result even the design process for the centre broke new ground. A well-known community architecture firm (Edward Cullinan Architects) was eventually appointed, even though not on the NHS list, and the project team was widened to 15, including representatives of the CHC, local GPs who would use the centre, managers and various therapists. The architects attended a vast number of meetings and drew up ten different designs for the site.

Staff were thus involved in planning the unit to a degree exceptional for the health service, although patient involvement was largely limited to the very active CHC representation. The building has proved popular with staff and patients.

Since the centre opened in 1985, considerable efforts have been made to draw the local community into helping run it. The most formal form of user involvement is the centre advisory group, consisting of seven staff and seven representatives of local organisations and individuals. This was set up in 1987, as part of Lambeth's general development of advisory groups (discussed in more detail in Section 6). The chair, always a lay member, is a full voting member of the centre management team. The group provides a forum for discussion of new ideas and issues of concern, and enables lay people to have an active role in the development of the centre.

It was envisaged that members of the advisory group might have a considerable role in dealing with problems and complaints that arose; the fact that this has not happened is perhaps more a tribute to the accessibility and sympathy of the staff running the centre than any failure on the group's behalf. The group sees increasing local involvement as a high priority, and has organised open days, a suggestions box, information about itself and about local services, and (is aiming to produce) a local newsletter. It has also been involved in health education and in forming a colostomy support group.

The group's contribution to policy has so far been limited, although as it mainly relates to the centre management team, which itself deals much more with day-to-day issues than with policy, this is perhaps not surprising. Yet some of the group's work has policy implications - for example, it picked up from management team minutes a debate about whether or not the centre should admit AIDS patients. The discussion which followed highlighted the need for more information before decisions could be made and the idea for a local study day evolved, which helped to shape the policy for admission of AIDS patients. Also by its very existence the group influences policy-making, reminding the centre management team to take the community viewpoint into account.

Setting up the group has proved a large part of the job of a community link worker attached to the centre and employed by the district health authority (DHA), although she has a much wider brief than this. The community is also involved on a more informal basis; local groups, such as carers or bereavement support groups, tenants' associations, and even junior judo, have meetings in the centre; various health education and other learning facilities are made available and there are special functions such as fetes, picnics and gardening days for local people and staff to meet and get to know each other.

In addition to the links with potential users of the centre in the neighbourhood, the centre fosters the autonomy of current patients. For example, the degree of involvement of staff in drug administration varies, with many patients having sole charge of their own drugs which they keep in a locked drawer and take or not as they choose, just as they would at home. Patients not only read their own notes, kept at the bottom of their beds, but are encouraged to contribute to them. And all patients have strict treatment plans with achievable goals which are subject to frequent review, and patients, and where appropriate carers, are closely involved in decisions about care and discharge.

Emphasis is placed on helping patients die as they wish; one was discharged home in the middle of the night so that she could die in her own bed - no mean feat of organisation. Managers of the centre feel that fostering positive attitudes amongst staff towards patient autonomy, including listening to what patients say, is what counts above all.

These two strands of user involvement (individual and collective) rest on strong foundations of teamwork - not just between different groups of staff, but spanning staff, GPs, managers and patients. Staff, far from seeing this as a threat to professional autonomy and credibility, feel that their working experience is greatly enhanced and that sharing some of their responsibilities with users has contributed to a good atmosphere and enhanced satisfaction for staff, patients and managers.

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Section 2

CONSUMERS IN THE NHS - the background

There is enormous interest in making health services more responsive to the need of users. The first Griffiths report (1) criticises NHS management for failing to talk effectively to users and staff about how well the service is being delivered at a local level. The Cumberlege report on community nursing (2) recommends involvement of local people at neighbourhood nursing team level. At the Scottish Conservative Party Conference in May 1988, Michael Forsyth MP, Minister for Health at the Scottish Office, emphasised the central importance of NHS users. The most recent NHS White Paper (3) reminds us that 'the patient's needs will always be paramount.' And the World Health Organisation Alma-Ata Declaration (4) contains a clear statement of principle:

The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

Outside the health service, a number of Labour-controlled local councils have substantially decentralised their services in an effort to be less remote from, and more accountable to, users. Both they and the Greater London Council experimented with a number of different ways of involving users.

Both moral and pragmatic arguments for involving users have been propounded since the creation of the NHS but until relatively recently they have had little weight. Now a commitment to consumerism is increasingly part of policy objectives, and national policies for primary health care, community care and hospital services, require increased weight to be given to user views. What has led to this major surge of interest in consumerism?

In Britain two strands which have played a part are an enthusiasm for citizen participation and the growth of the wider consumer movement during the 1960s, coupled with the much more recent influence on service provision of market models.

A DEMOCRATIC TRADITION

The British tradition of participatory democracy argues that people have a right, some would say a duty, to participate actively in the way they are governed. During the late 1960s there was growing concern that bureaucracies were becoming bigger and more distant from the people they were supposed to serve (5,6). Initially, the focus of groups challenging the bureaucracies and arguing for users to have more say was heavily directed towards local authority provision such as housing, planning, and education. The demands and assaults on local government have led to a series of practical responses (7,8) and much can be learnt from their experiences.

Initiatives in health and the wider public arena slowly gained momentum within this context of growing consumer awareness. The Consumers' Association, founded in 1957, built on its experience of comparative tests and began to campaign for improvements in goods and services. The Patients' Association, founded in 1963 'out of a burst of indignation' (9) at unethical experiments on patients in hospital, began to acquire a reputation as a thorn in the side of the health professionals.

It was against this backdrop that community health councils (CHCs) were established as part of the 1974 reorganisation of the NHS to represent the views of local people to NHS management. This created, in theory at least, opportunities for high profile and well organised statutory involvement of users in NHS decision-making. CHCs have developed different styles - some have aided *individuals* in making better use of existing services by providing information and helping to redress grievances (10). In a similar way, the independent College of Health, founded in 1983, helps individual members make the best use of existing services. Other CHCs have developed their role as community organisers and helped to empower different *user groups* to work collectively towards more appropriate services (11). The self-help movement has also been a lever for change, brought about by experience of user groups. And the women's movement in particular has had a considerable influence on services for women.

Changing attitudes towards the welfare state have contributed to these developments. Many of the efforts to involve users or hear their views were also intended to make the state's bureaucracies more flexible and responsive. Such approaches often focused on the potential role of public sector management and provision in combating deprivation, disadvantage and discrimination. On the basis of underlying attitudes such as this it is not surprising that methods of participation chosen have aimed, often through community development (12), to empower traditionally disadvantaged groups; to promote collective action rather than individual redress; to offer some degree of power-sharing within the decision-making structure; to acknowledge that the service might be changed to suit users rather than the other way round, and that professionals may not always know best.

The language of these methods reflects the philosophy. For example, users rather than consumers, in recognition of the differences between using services and purchasing goods; *community groups* as opposed to 'the public' (acknowledging the diversity of the population being served); *involvement* rather than feedback, implying a more active relationship; and *empowerment* rather than unsupported information-giving or making 'better' decisions on the consumer's behalf. We have used this language in preference to commercial terms because it more accurately reflects not only the complex nature of relationships between providers and those using services, but also the heterogeneity of the population.

Such challenges to the power of the bureaucratic welfare state have not taken place without considerable debate and even turmoil. The liberal left and centre of the political spectrum provided the impetus for the introduction of the welfare state, and as its architects, many were slow to accept that it might be insensitive and over-bureaucratic. Yet at the same time, many of the initiatives in recent years which empower users have also come from the left of the political centre. And in local government, from the late '70s onwards, notable efforts to involve users have been made by left-wing Labour councils.

Britain's experience has not been unique. In Sweden, for example, a recognition of the gap between public agencies and users led to a concerted programme from the specifically created Ministry of Public Administration to reorientate the public sector towards the users, and the strategy includes both national and local government (13,14). A package of reforms has been developed which maintains the objectives and quality of the welfare state and at the same time aims to provide greater freedom of choice for users. The strategy adopted is to strengthen the position of users by enhancing the scope for them in local decision-making. State grants are available for experimentation. One area being explored is 'conditional delegation', i.e decision-making powers being delegated to employees on the condition that they consult with clients before taking that decision.

Doubters and critics

Advocates of participative approaches in the health and social services have not been without their critics. It is sometimes suggested, for example, that most people couldn't care less how and where local services are delivered - until they happen to need them. However, this contention is often based on dubious evidence. Attempts at participation are criticised in principle for what are in reality practical failings, such as expecting people to 'participate' in poorly advertised, badly-timed meetings that are hard to reach by public transport.

On the other hand, the enthusiasm and commitment demonstrated by the women's movement over childbirth issues has been widely acknowledged. And many other examples of local community health initiatives demonstrate a collective desire to become involved (15-17).

'Participation' is also criticised on the grounds that it merely serves to increase the power of those who were already relatively powerful service users, namely the articulate middle classes. And it is true that such people are often over represented. However, it is because of these imbalances in some of the existing representative structures that special effort needs to be put into reaching other groups in the population who are difficult to reach. Health professionals who have recognised this have borrowed and adapted techniques from community workers to reach out into the local community (18,19).

Apart from the likelihood that doubts about representativeness will delay managerial action, there is also a danger that any resultant innovation or change is damned as a concession to pressure from 'unrepresentative' groups. This may mean that hard-won improvements have to be renegotiated time and time again. For example, the National Childbirth Trust has sometimes been accused of being middle class and extremist in its pressure for 'natural' childbirth. Whatever truth there is in such an accusation, it does not mean that the National Childbirth Trust's contribution (and the debate it has fostered) has not benefited other users of maternity services. This fact does not prevent constant challenges to the legitimacy of NCT's campaigning role.

LESSONS FROM THE MARKETPLACE

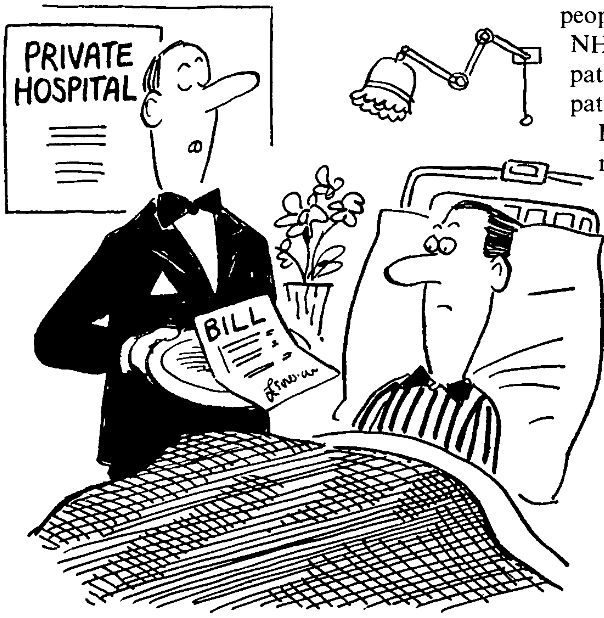
The new element in the current consumerist wave is a willingness to learn from the market economy. An interest in the techniques of commercial enterprise is now widespread amongst public sector managers. It is very much in tune with the 'enterprise culture' and the ideas underpinning it. Central to these ideas is the notion that there should be a substantial reduction in the role of the state and an increase in choice, a key concept.

Exercising choice is seen as an individual (or family) activity rather than a collective one and as a question of exercising informed consumer rights rather than directly involving oneself in running services. In the health field this belief is reflected in the increasing numbers of people with private health insurance and the growth in private health facilities.*

Many private services genuinely operate in the context of the market place: components of the service are itemised on the bill; services and facilities are advertised; discounts are offered on operations performed during slack periods; and customers must be satisfied enough to come back again. It is therefore appropriate in this context to use the concepts - and the language - of the commercial world, such as market research, publicity drive, packaging, consumer choice.

In the context of the NHS their use may have fundamentally different connotations. What is 'choice' in the NHS? Can most people really 'shop around' for packages of health care in the NHS? What are the barriers to choosing and changing? Do patients consume services or do they *use* them? Do some patients neither consume nor use services, but *receive* them? It may look very dynamic to be in command of completely new jargon, but this can lead to nothing more than superficial relabelling - for instance calling patients customers. The NHS and the commercial world are not neatly interchangeable.

In the commercial world consumers' purchasing decisions largely decide whether a product succeeds or fails. Market research is designed to *predict* consumer views (to locate potentially profitable products and avoid mistakes).



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*Between 1979 and 1988 UK private acute hospitals increased from 149 to 207 (Source: Survey of Acute Hospitals in the Independent Sector IHA, 1989).

Between 1979 and 1986 people covered by private medical insurance rose from 2.75M to 5.25M (Source: Weekly Hansard No 1434, 18-22 January 1988).

Advertising and packaging is used to *influence* them. In the NHS consumers do not generally choose what treatment they get, or where and when they get it - although currently users do have limited choice in certain areas, for example whether to have family planning services from their GP or a community health clinic. Market research in the NHS can therefore been seen as a *substitute* for sales information about purchasing decisions - something which can provide periodic 'snapshots' of what customers really want. Similarly, advertising and publicity may perform a slightly different role in the NHS than it does in the market place. For example, advertisements usually aim to persuade consumers that a particular product is desirable. In the NHS, managers may borrow some of the techniques from advertising for a number of functions *other than* persuasion e.g consultation on priorities. Of course, the techniques are also widely used for persuasion purposes, particularly in health education.

This notion of market research as a substitute for a real market has led to considerable enthusiasm for these techniques. Managers who ten years ago might have dismissed the suggestion that they could learn much from commercial firms are enthusiastically discussing marketing approaches, consumer surveys etc.

Market Methods

Griffiths recommended the use of market research, among other methods, to find out about the experience and perceptions of patients and the community (20). Indeed, the implementation of general management in the NHS was heralded by an influx of 'outsiders' with management experience.

However, so far the cross-fertilisation of market methods and the NHS has proved disappointing. Too often it has resulted in unimaginative 'copy-cat' surveys, and at worst it has given the impression of activity in order to disguise inherently unimproved services. Surveys are commissioned to measure the satisfaction of people already using health services (patient/user satisfaction surveys). In some areas, information about NHS facilities and services, particularly screening, has been disseminated using techniques borrowed from advertising and public relations. How useful have these exercises been?

Jones et al (21) point out that many surveys have yielded disappointing returns either because they have been poorly executed or because insufficient attention has been paid to translating findings into policy and practice. It *may* be that a more rigorous use of market research and marketing techniques would help to avoid these problems. For example, marketing and advertising strategies in the commercial sector include targeting techniques designed to reach defined 'target markets': e.g women and/or men in certain age groups; young, black people; people of pensionable age. It is not difficult to see how managers in the NHS could adapt such techniques - *so long* as clear thinking had gone into defining and prioritising the target groups, *and* if the appropriate techniques are then used. In other words, the pitfalls of using methods from the commercial world often lie in poor understanding and execution of the techniques, rather than the techniques being inappropriate in themselves.

Significantly, it is mostly the simplest aspects of marketing and market research that have been adopted by NHS managers. It may be possible in the future for the NHS to adopt a more sophisticated approach to its borrowing from the commercial world; e.g by learning *how* to identify and access target groups; by facilitating informal discussion amongst users; by building on techniques used in intimate market research; or by conducting sequential exploratory research to build up a picture of changing needs.

On the other hand, enthusiasm for the new techniques may mean that the questions that they do *not* address are relegated to the sidelines. For example, market research is not usually interested in preferences, only in what economists call 'effective preferences', i.e not in who would like a washing machine, but in who has the money to buy one and would choose to spend their money in this way next. (So, for example, an incontinent disabled person on invalidity benefit may have an urgent need for a washing machine but cannot afford one and so would not be indicated by research as a marketing target.) Similarly, commercial techniques tend, on the whole, to be geared and developed towards targeting social classes A, B and C rather than, say, single homeless people. The very different aims of the NHS and the washing machine company do not invalidate the use of similar market research techniques but it does mean that there needs to be some sophistication and vigilance in their use.

ACTION NOW

The pressure for more participation in public services, at the same time as the pressure for the introduction of market approaches in the NHS, has created a lot of discussion about involving service users. Politicians of all shades have an interest in this area. In addition, the Department of Health, regional health authorities, district health authority members, local authorities and other groups with whom managers will have contact are increasingly expecting signs of action. Involving users is becoming a major management task.

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AIM FOR PRECISION

Before managers commit themselves and their units to trying to gear services towards the people who use them it is vital to make some honest decisions about what the goals are. Is an advisory team, for instance, an attempt to gain *information* about users' viewpoints on which to base decisions, or to have users actively *involved* in decision-taking? What balance of power between service providers and users is envisaged? To what extent can restructuring of services be contemplated, and how much is the aim simply to improve the 'marketing' of existing services?

Of course, not all of these decisions are always in the hands of managers. Health authority members are likely to get involved depending on the scale of the proposals. It may be helpful to draw up a district policy or 'user strategy' to give some framework and rationale for any planned initiatives (see figure).

However, managers do not necessarily need to wait whilst a wide-ranging policy on user participation is drafted and re-drafted. As we shall see later, there is already plenty of evidence to suggest which services need changing to make them more responsive to users, and to show that relatively small scale developments can have a big impact.

Once managers are clearer about the aims and scope of any attempts to build in user views, decisions about how to achieve this also become easier.

OUTLINE STRATEGY

A district or unit strategy for making services more responsive to the needs of users would include:

- a statement of commitment not only to finding out what users think but to finding ways of implementing changes
- an outline of the ways in which user involvement and feedback can be promoted

  e.g links with local groups
  community representation on committees
  consultation forums
  market research
- an outline of the ways in which the district/unit could enhance the acceptability of its facilities and services to the community it serves

  e.g shop-front training
  providing information about services
  improving access to services
- a description of formal structures for the flow of information between users and service providers which maximises the impact of user views

  e.g informal walkabouts
  user representation on committees
  issues raised by front line staff
- an indication of the potential roles of different groups of staff within the user strategy.

CHOOSING THE RIGHT APPROACH

What are the manager's goals? If these are clear it will be easier to select the right methods for achieving a successful outcome. For example, if there are plans for a review and centralisation of clinics in the community, there are a number of options for a community unit manager who wants to involve local people in the process. A manager conscious of the public image of the authority might feel the need to legitimise what is perceived by him/her as an inevitability. This might lead to an effort to explain the plans in a way which persuades people to draw the same conclusion as the manager. Such efforts often lead to the publication of a 'consultation' document, or simply an enthusiastic press release.

Another manager might want to collect reactions to proposed changes so that services are made more accessible for users who do not attend the clinics. A survey or talking to clinic staff might yield this information. Extrapolating from studies done elsewhere might also help. These findings could then be taken into account in planning decisions. Thirdly, local people could be asked to consider the problems and develop their own solutions, with a commitment to act on them as far as possible. This might involve distributing understandable background and options material among a wide range of community groups and the community health council. It might mean public meetings, to allow more information to be given and discussed. It would involve detailed recording of, and follow-up discussions about, the suggestions, recommendations and anxieties of local people.

Having found out what people really want from their local clinic, what happens next? Managers may well hope that users' views do not markedly differ from their own, and that suggestions are limited to minor changes such as more chairs in waiting areas and do not extend to recommendations about having district nurses on duty at night. Would a manager be prepared to recommend changes to existing policies or proposals in the light of information from the community? Even when this means reopening discussions on policy decisions that have already been made, or supporting extensive restructuring of services?

Is a survey called for, or would a users' forum be better? Is it a question of seeking views on proposals for new services, or of gleaning responses to existing services? The methods chosen will depend on the aims. For example, if the aim is simply to monitor the effect on patients of planned changes to health services, evaluation can be built in from the start, perhaps using a team of researchers and planners. If the aim is to ensure that all community health services take account of users' views in the planning and delivery of services, the establishment of user forums, user representatives on planning teams, and so on would need to be considered. This scale of activity implies a commitment of resources and management. It may require the use of temporary facilitators to reorganise the unit, build staff commitment and make links with the community.

Clarity about goals and what is on offer will increase the quality of contact with local people, whether this is via a survey or a user forum. The inevitable discussion and negotiation about roles and responsibilities (see Section 5) will also come as less of a surprise.

Budgets

Attempts to gather users' views have often become hollow exercises because not enough support and resources have been allocated. Proper resource planning is much easier when aims are clear.

A public briefing document, which aims to inform rather than consult users and smooth the way to a change in services, could be relatively cheap. Support might be needed if the document provokes angry responses. Involving local people in planning and policy making for community health services has considerable support and resource implications. A joint planning committee might be one way of realising this aim and on paper such a committee has low running costs. However, for it to be really effective, rather than window dressing, implies spending time getting to know local groups and community organisations, followed by thought and joint discussion about how *different* perspectives and interests might be incorporated into decision-making. The continued and productive involvement of local representatives (see Section 5) by arranging briefing meetings, and preparing appropriate background information, also takes time and effort.

Sustaining innovation

Even where services are recognised as having flexible and responsive attitudes towards users, considerable effort is required to sustain positive attitudes. This is made simpler if aims are clear and have been precisely stated. For example, the Lambeth Community Care Centre (see p 7) has an explicit policy about patient autonomy and flexible staff attitudes. Sustaining the positive approach of the centre has been much easier because there is a written policy and a management responsibility to ensure that infringements are monitored. Lambeth managers have kept a close eye on practice and attitudes, and regularly set time aside to see how well or badly they are matching up to the policy.

The following case study highlights some of the practical difficulties of getting started. Even if ideas appear to be clear at the beginning, the day-to-day stresses and changes in NHS management will remorselessly unearth things that could have been better thought out or better prepared. The case study demonstrates the problems of working in isolation, of failing to generate commitment throughout the organisation, and of using broad-brush, rather than carefully targeted, techniques for making services more accessible to users.

CASE STUDY: *Good intentions, muddled ideas: a community clinic*

The health visitors and nursing officer working in a clinic wanted to make it into a focus for the local community. They felt that the clinic was an underused local asset, and that the health visitors were failing to meet local needs and should extend their client group beyond mothers and babies to include more elderly and middle-aged people, and schoolchildren. They also wanted to extend their role to become health advisers and counsellors.

The health visitors believed that offering an improved service would give them more satisfying jobs. They put considerable time and energy into planning how to achieve these goals. Yet much of the project never got off the ground and in the end the service remained virtually unchanged.

Although some reasons for this, such as staff changes, were outside the project's control, lack of clear ideas about how best to achieve the changes they wanted weakened the project from the start.

The clinic staff made plans to inform potential users of what the clinic could offer, assess need and gather views on the proposed changes, and to evaluate the scheme. They decided to start with a broad approach to publicity, rather than targeting specific client groups. They prepared a leaflet (in English only) which was to be distributed through letterboxes. The household delivery, together with local display of a matching poster, was to coincide with an open day at the clinic.

For the open day, stalls on diet, dental health, Pensioner's Link, videos, hypothermia advice, relaxation and mothercraft classes were all planned, with balloons and badges publicising the clinic. It was hoped that the open day would help identify users' needs and views. People coming to the clinic open day were to be given a questionnaire.

Plans were made to reorganise working arrangements so that health visitors made appointments for home visits, cutting down on the number of visits where they saw no-one. Each health visitor would staff the clinic for a day a week for drop-in use. An evening clinic was planned for working mothers to bring their children.

Fortunately, the clinic was due for upgrading and offputting and badly signposted reception arrangements were to be replaced by a more welcoming reception area. A structured interview in the form of a questionnaire was commissioned, which aimed to find out what people thought about the clinic and to identify ways of making it welcoming and user-friendly.

Those involved with the project were anxious not to reinvent the wheel and made a number of valuable contacts with others who had developed similar schemes. Evaluation was planned from the beginning and records were kept to facilitate this. The health visitors met regularly with their nursing officer to review progress, starting well before changes were implemented. This was designed to ensure the full involvement of those carrying out the scheme, and to ensure a quick response to problems as they arose.

However, after an initial period of enthusiastic planning, things started to go wrong. The nursing officer had discussed the plans with the Director of Nursing (Community) and they had been agreed by the unit management team. But this was immediately before the Griffiths reorganisation and the changes of staff which resulted from that, together with readjustment to the community unit budget, forced the unit to reassess what it could achieve.

The unit management team decided that the project should go ahead, that the structural improvements would be deferred for a year and the open day postponed until they were completed. Also, the leaflet and poster would be abandoned, there would be no publicity other than a letter to existing users, and the attitude survey which had been commissioned would not be used. Only the proposals for appointments for home visits, drop-in sessions and a general commitment to extending the health visitors' role and client group remained.

These proposals had not been designed to stand on their own. The success of the project relied on the publicity generated by leaflet, poster and open day, and on responding to the views of users through the survey and the open day. It also relied heavily on the enthusiasm of the health visitors and nursing officer, who feld understandably demoralised by the abandonment of so much of their plan and by the deferment of the improvements to what they felt was a very unsatisfactory clinic.

This disillusionment may have affected the amount of energy put into implementing the proposals. There was little attempt, for instance, to overcome the collapse of the publicity campaign by, for example, building up contacts with local groups who might have been able to support the project by publicising the changes and providing consumer input. As it was, there was no-one other than the staff directly involved to defend the proposals, as neither local groups or other professionals had been involved in drawing up the plans. Indeed, other groups of health workers and administrative staff had been passively dubious all along, an issue that was not really addressed.

The new working arrangements were introduced. A preliminary evaluation found the drop-in sessions were underused and almost only existing users - mothers and babies - were attending them. This was hardly surprising since they were the only people who had been informed of the changed arrangements! The important aim of spending more time spent in face-to-face contact was not met. There was only slight evidence of an expanded role for the health visitors and attempts at proper counselling sessions were often frustrated by the receptionist continuing to put 'phone calls through. The weekly evening clinic was little used.

There was no way of knowing what people thought of the changes or if they had even heard of them. A number of specific problems arose - for example the health visitors who ran the well attended drop-in sessions which happened to coincide with an immunisation clinic acquired a disproportionately heavy case-load and health visitors had to spend time liaising with colleagues because they now 'shared' clients. In the absence of any evidence of major benefits to staff or users there was little motivation to work through these problems. Shortly after, apart from the appointment system for home visits and the introduction of a monthly, evening clinic at a slightly later time, the scheme was abandoned.

The experience at this clinic highlights several points:

1 A general desire to improve

services needs to be translated into clear, and connected aims. The health visitors had good ideas about reshaping services at the clinic but translated the ideas into unrealistic plans. This had a number of spin-offs. One problem was the lack of clarity about how they were going to make changes, which made it difficult to argue their case when unit priorities were re-examined. And a second problem was that the loosely connected tasks were collectively weakened when some were abandoned.

2 Getting managerial backing for initiatives, however small-scale, is essential. Not only does this help to tie proposed developments into a wider framework of objectives and priorities, it also adds resilience to projects which might otherwise be in a weak position to fend off cuts. It is also worthwhile getting backing at authority level for initiatives which are attempting to make services more user-friendly.

3 Preparation work is essential. There should have been explicit plans for building commitment amongst other staff who were obviously going to have influence over whether or not the tasks would succeed. Some support staff were unclear about their changed roles, let alone committed to them. There were attempts to communicate plans, but because these remained vague, it must have been difficult for the other staff in the clinic to understand what was being expected of them.

4 The attempt to make the clinic accessible and attractive to all groups in the community meant that efforts were spread very thinly. There was an implicit recognition that some groups of users were losing out, yet no attempts were made to target disadvantaged underusers of the clinic facilities. What's more, the methods selected to reach 'the community' would have actually excluded some groups who currently underused the services, namely people whose first language is not English and people who have difficulty reading. A broad-brush approach is not a good way of reaching people most in need - for them the clinic would remain inaccessible.

MONITORING AND EVALUATING PROGRESS

How will the methods selected to involve users be assessed? This is quite a subtle and complex area in itself, though once again, if you are clear about your aims it will be easier to decide how to evaluate your chosen method. However, the approaches we describe, in the case studies and elsewhere in the book, have varying timescales. Some need to evolve slowly, developing into activities which are more closely allied to the needs of local individuals and groups. It is important to recognise that developing more responsive services will take time (as well as being time-consuming) and that this is not an area for instant results.

For example, the long-term goal may be for local people to play a large part in setting the guiding principles for a particular service. Although this is the implicit overall aim, in only a few user activities may people be seen to be involved in developing 'policy'. Many initiatives focus on tasks, nitty-gritty details and problem-solving, rather than in guiding policy for particular services.

The West Lambeth Centre Advisory Group, for example, which is linked to Lambeth Community Care Centre (see p 7), feeds user views into health authority decision-making through the centre management teams. However, this is unlikely to influence *policy* since the centre management teams deal largely with operational matters. In Haringey's work with black and ethnic minority groups (see p 36), the community input was directly into planning teams (via sub-committees) with the aim of influencing general policy. Again this has happened only to a limited extent. Attention so far has mainly focused on tasks such as producing information leaflets, and setting up helpline and advocacy projects. Steps have been taken to develop joint policy with police, hospital and social services on problems with the use of section 136 of the 1983 Mental Health Act (1).

What emerges clearly is that first the structures which managers establish have to reflect their aims. Direct involvement of users in policy-making will only happen if opportunities are deliberately created. This may mean fostering involvement at existing policy making levels, or by decentralising policy making to levels where people find it easier to contribute (2).

Secondly, it is unreasonable to expect people quickly to feel at home with bureaucratic ways of working. The transition is likely to take time and will need much support (see p 35). Also, a period of working together on specific *tasks* is often a way of developing group cohesion and confidence through achievement, necessary precursors to the more abstract and long term arena of policy-making.

Sometimes, however long initiatives are allowed to run, they never get off the ground. Why? Maybe the initial aim was inappropriate for the service and for the local community. To take a dramatic example: the aim might have been to involve black and ethnic minority groups in developing local policies for the 1990s for the care of babies with AIDS in the community. The attempt might be a flop, simply because the black community perceives concerns which need more urgent action. It is a manager's responsibility to find out what these are before setting objectives.

Outcomes which do not tally with the original aims may not necessarily be a sign of failure. Even when user initiatives do not directly influence policy making, they may still have considerable influence on the way in which services are delivered.

The production of one leaflet in different languages, for example, accompanied by an investigation into which languages are most needed, consultation on content, and new methods of distribution, may greatly influence the future work of a particular service without any formal policy decisions being taken. In addition user initiatives which do not mirror the original aims can also help to identify what issues are *really* important for local people. The babies with AIDS would be a case in point.

It is important that managers setting aims for the service do not create an environment which excludes any community-led initiatives. Re-shaping services and making them more appropriate requires listening to and acting on what users say. This means recognising and valuing campaigning, 'watchdog' activities and vociferous 'complaining' as part of the process. Activity based in the community is not likely to subside once you've got one 'user rep' on a Joint Care Planning team. You also need to be aware that proposals generated *inside* the service tend to put the needs of the *organisation* first and to develop structures which reflect this. Suggestions and demands from outside the organisation help to challenge patterns of thought too ingrained to be changed from within.

In summary, being clear about aims will help you monitor progress towards a more user-responsive service. Try at the same time to allow reasonable time for some aims (especially for user involvement in policy-making), and to allow for changes in priorities and approach if different issues emerge as important for local people.

References

1 HMSO. *Mental Health Act 1983*. Part X (Miscellaneous and Supplementary), s136 mentally disordered persons found in public places.

2 Dunford H and Hughes J. *Pimlico Patch Committee - an experiment in locality planning*. Riverside Health Authority and King's Fund Centre, 1988.

Section 4

GROUNDWORK IN THE NHS - roles for managers

The development of user friendly services is a major management task. Throughout the 1990s it will mean the development of new, and potentially exciting roles for managers. This section offers a checklist for managers to help them carry out essential groundwork within the organisation. Many of the questions may seem obvious, yet overlooking them will cause problems later on.

WHERE TO START

It makes sense to start where there is a good chance of achieving change. Sometimes a good opportunity may arise simply because staff have already taken the initiative. An imminent service review, a group of staff interested in making improvements, changes at a policy level that may raise the profile of certain services - may all present good prospects for setting the ball rolling. West Lambeth (see p 53) capitalised on developments in the priority care services and linked the idea of local advisory groups to new centres in the community. Districts which are planning community care services will undoubtedly have opportunities to develop on-going contact with users of services and other local people.

Staff anxieties and enthusiasm

Management enthusiasm for consumerist approaches will be dissipated if it is not matched throughout the organisation. Lack of support elsewhere will hinder not only attempts to set up systems for users to be involved, it will also limit opportunities for the implementation of any other changes in services that are recommended.

In many of our examples, it is staff who are closest to service users who have taken the first steps. They are often in a good position to identify shortcomings. However, the nature of the patient/professional relationship means that staff in direct contact with patients are often the most wary of more patient/user involvement. In order to cope with their jobs they may have developed ways of interacting with patients that allow them to feel in control, and management talk of increasing user involvement may be interpreted as implicitly criticising staff or as a device for checking up on them. The idea of giving users more say is threatening. Middle managers might also feel threatened and anxious at the prospect of, for example, a 'flood of unrealistic demands'.

These fears need to be discussed openly. There should be opportunities to discuss the positive aspects of user involvement; not just its likely impact on the quality of the service, but also how it affects the work and satisfaction of staff and managers. Meetings with managers and staff in other authorities who have tried something similar could help reassure staff about levels and types of expected demands - usually not for bigger and better hospitals, but more likely for information about services.

One common mistake is to make decisions about new ways of working at only one or two levels in the organisation. This could be at district management or health authority level, or at another managerial level, or at operational/field level. Unless the decisions and the principles behind them are then communicated and discussed at other relevant levels of the organisation, ownership of the ideas and their implications is minimal. It is unrealistic to expect people working in the service to understand the ideas or give them any backing. Communication and commitment-building is much easier if things are written down, and if formal attempts to communicate principles and proposed new practice are set up, for example, open meetings for staff. This process need not be 'top down'. For example, in the case study (see p 22) on increasing clinic access the group of health visitors might have been better able to withstand the changes which were imposed by management if they had communicated the principles of what they were trying to achieve to a wider group of people in their district.

One of the key functions of the development worker in Haringey (see p 36) is to build commitment within the health authority for increasing the involvement of black and ethnic minority users. By persuading people that this is important she has managed to create a caucus of enthusiastic health authority workers who are helping to achieve this. It is clearly better if success is not wholly dependent on one or two dynamic individuals.

The challenge of change

Generating enthusiasm and commitment for the idea of user responsive services is essential. It is also vital for managers to support staff who are putting theory into practice. For example, introducing user representation on decision-making forums (planning teams, advisory groups, neighbourhood forums) unquestionably shifts the balance between health service workers and service users.

Health workers are usually in control of the relationship with a patient/client. They are powerful because they know their way round the 'system', their expertise gives them status, and they are secure in the knowledge that for most situations their experience and skills are relevant. Groups of users might challenge the basis of this relationship because their collective knowledge and experience helps to empower them and enable them to question existing provision and practice. Professionals therefore have to try to develop a different relationship with *groups* of users.

For many health workers, this new relationship is very difficult to cope with, especially if they feel that traditionally 'grateful' patients will become critical of the services provided if they get together with other users. It is even more difficult to tackle these anxieties when health workers themselves feel under-valued and powerless in the organisation and have no effective channels for contributing their views about how services are run. The potential for unproductive conflict here is enormous. Managers need to help staff realise what to expect - and need to create opportunities for collecting and using staff views. Staff also need enough power to make decisions and suggestions in meetings with user groups. They also need guidance on ways of facilitating productive contact (see Section 5).

The options - a checklist

It is useful to think beforehand what the user's eye view of existing services might be. This does not remove the need to make contact with users in a systematic way but rough indicators can be gleaned without elaborate research. For example, the type of complaints received may indicate, at least in part, the changes that are needed. Talks with field staff and other managers can yield information about delays in getting treatment or supplies, poor communication procedures on discharge, or the need for better links with other important agencies. Walking around clinics and health centres and simply talking to users might give a better impression of where the service is failing than months of survey work. When a clearer understanding of some of the problems is reached, the next task is to think about some of the obvious changes that would help to make improvements.

The purpose of this forward-thinking exercise is threefold:

i) to make managers more acutely aware of some of the shortcomings of the service. As direct contact with users is increased, at least some of the feedback received will not be a complete surprise, and may help in thinking through ideas for changes to services.

ii) to give managers an opportunity to measure their own perceptions of the quality and appropriateness of the service against those of users. If there is an enormous gap, the links with users need to be further developed and strengthened. If there are obvious similarities, the next step is to work together on the *solutions* to some of the problems. Either way, further contact will be necessary.

iii) to give managers a rough idea of the *scale* of change that might be needed. This will only be a rough idea since if no direct contact with users has been made, their needs and demands can only be guessed at. Managers might be thinking about pram parks, users might be aiming for a radical look at clinical times, or the removal of a particular, racist member of staff.

The preliminary 'fieldwork' can only provide part of the picture and cannot replace direct contact with local people.

Section 5

PREPARING THE COMMUNITY - roles for managers and staff

Working with staff to gear services more effectively towards involving users needs to go hand in hand with developing good links with local people. In this section we offer a checklist to help plan how best to do this.

We have not specified *who* should undertake the various tasks. This is partly because the structure and size of individual units varies so much, and partly because some of the issues affect all levels of responsibility. Some health authorities might be fortunate in having community development workers to do some of the outreach work necessary to involve and inform local people. Others may wish to use existing staff. Whatever individual units or authorities decide, it is important that managers recognise the diversity of roles which need to be covered and build them into legitimate tasks for all groups of staff - including locality managers, neighbourhood nursing team managers, administrative staff and community nurses.

The strongest message for all staff is the need for thorough preparation. It is essential to spend time going to meet groups on their own territory to share agendas. The process is not quick, nor is it easy. The development worker's experience in Haringey Health Authority (see below) shows that building and maintaining links is a *continuous* part of the participative process and that managers should be prepared to meet groups on a regular basis.

THE HIDDEN USERS

Plans for reviewing, say, the services provided in a health clinic are unlikely to include a full-blown district-wide survey - even if this would yield the right sort of information. Therefore there is a need to identify those groups of the population most likely to be affected by changes and those who should have some say in how things are done. In the case of a health clinic these would obviously include existing users, but also groups which could perhaps make *more* use of services, such as teenagers, elderly people, isolated parents.

It is helpful to focus activity on selected groups which you have identified, for whatever reason. There is an inherent conflict in trying to provide a comprehensive service to a population with complex characteristics and needs. You may decide to put *equal effort* into trying to reach everybody. Or you may decide to concentrate on *specific groups* within the community which you consider need the services most, and which at present do not use existing facilities. The implication of the latter approach is that those with *less* need might lose out. But more significantly, if efforts are spread evenly but thinly, disadvantaged groups may well fail to benefit at all.

Positive action is needed for some groups to get the same out of existing services as everybody else. Working out which groups to aim to involve in discussions about services is essential and requires consultation amongst field staff, local community groups, councillors, community leaders and social service staff. This sort of environmental scanning ought to be continuous in order to pick up changes in the local community which might influence the nature of target groups and priorities. However, long drawn out priority-setting should not be used endlessly to postpone practical attempts to involve users.

Do your homework

Identifying priority groups and thinking clearly about them will influence the choice of methods you use to contact and involve them. It is best to start with the characteristics of the groups and then design the best approach. For instance, how large are the relevant groups? Do they have particular age, class or ethnic structures? What characteristics make it a 'group' (geography, membership, current use of services and facilities)? Are all members of the group mobile? Do some have transport problems? What times of day are they likely to be able to attend meetings? Or do they need respite from caring?

It is not a good idea to start with one model for contacting community groups which you later tinker with to make it slightly more 'relevant' to other groups. Do not, for example, gather views from elderly people and only later think about what would be different for black elderly people, or elderly people with learning disabilities.

BE CLEAR ABOUT WHAT IS ON OFFER

Be absolutely clear about what sort of relationship you are proposing to have with local groups and individuals and make sure that you communicate your intentions to them. Health authorities are sometimes seen as jumping onto a 'consumerism' bandwagon, years after local community health initiatives have started to work with field staff or local authorities to change the pattern of service delivery. New overtures from different staff, expressing vague ideas about getting closer to 'the consumer' are likely to be viewed with suspicion by groups who use a different language and are sceptical about the sorts of relationships and changes possible. Even if you are sure that you simply want to establish better consultation mechanisms, and you manage to communicate that message effectively, you may yet face hostility if local people have played a much stronger role in different arenas. You won't be offering them much.

Be sure to bring out into the open the scope of any groups, forums or teams you establish. For example, what does the term 'advisory' mean? This needs to be discussed so that everyone involved is clear. Use examples to illustrate what the forum or meeting may or may not get involved with. Be specific about what will happen to ideas and suggestions: it is not enough for managers to say always that they will try to take things 'on board'. They should explain: how other decision-making structures within the unit/health authority work; explain timetables; and spell out some of the things that might cause delays.

Oiling the wheels

How can you help groups of users or potential users to become involved? User-involvement at anything more than questionnaire level, is likely to mean attending meetings. Meetings vary depending on their purpose and formality. However, there are some general principles which managers should recognise in order to make meetings successful.

It is easy to cite apathy as the cause of low attendance at public events and meetings. There are usually other explanations: insufficient notice; lack of helpful information about the reason for the meeting; poor access to the venue; bad timing. Sometimes people have been put off by previous meetings full of jargon and unfamiliar committee procedures. Managers need to think about ways of overcoming the barriers that so often separate bureaucracies from the communities they are supposed to serve.

Meetings should be held in well known public places, and easily reached by public transport. People with disabilities must be able to get in. When meetings are held in large health centres or hospitals there should be good signposting (in appropriate languages) and/or reception facilities. It may be necessary to consider signers for deaf people, large print for people with visual handicaps.

Even if people can get to the meeting without difficulty, the setting may be intimidating for some. Why not consider holding more meetings in the established meeting places of local people and groups? Most football teams would think it unreasonable to expect to play all matches 'at home'. And what about regularly rotating the chairmanship of meetings? It may also be helpful to offer health authority premises as a meeting place for community groups so that they become familiar with the meeting environment.

WHAT DO USERS NEED TO KNOW?

Many of the people we spoke to who have tried to make services more 'user-friendly' unearthed a desperate need for more information about where, when and how services are provided. People also need to know about how they can get involved.

One way managers can help is to publicise the various committees and teams which *already* have user representatives and the names and organisations of local people involved in health authority decision-making. They should also explain how users can get involved themselves.

Secondly, if you are arranging an event which you want users to come to, make sure they really know about it. For example, if you hold a consultation day on the future of the chiropody service, you need to explain the context of the day and when and how users' views will be fed into the decision-making. Avoid jargon and abbreviations, and allow time for briefing meetings, so that representatives are not plunged in at the deep end.

Users are users, not bureaucrats

The Haringey experience (see below) has also shown that establishing contact requires considerable effort. Local voluntary organisations and community groups rarely operate in a bureaucratic framework. For example, for some groups it might be optimistic to *assume* that telephone messages and letters will be answered: after a reasonable time you will have to follow them up. Community group responses to requests for information or ideas might not fit very easily into the cycles and papers of NHS committees. Don't automatically assume that it is the groups who have to adapt. Users can offer fresh perspectives on the compartmentalised NHS planning and management structures.

Show that you mean it

There are other reasons why your initial contact with local people may be unproductive. Cynicism about heavy-handed attempts to contact users is widespread and understandable, particularly if there have been 'consultation exercises' that have left people disillusioned and frustrated, or if local groups have had long experience of forcefully expressed views being systematically ignored. You need to convince groups that their time and effort will be usefully spent.

The best way of doing this is by *demonstrating* that your authority has a commitment to listening properly and to improving services as a result - not an easy task. Some health authorities have a history of collaborative ventures with CHCs which could help raise credibility, although that depends on whether the CHC is effectively linked with other local groups. Other health authorities offer financial and other support to local projects and groups. Some have transferred underspent money to local community health initiatives. Another option is to offer expertise to local groups, such as help with preparing grant applications, support for designing and analysing community surveys.

At the end of the day, you might have to accept that there will be some groups who, for whatever reason, do not want to respond to your overtures. For example, some black organisations may not want to get involved because they do not want to collude with systems which, they feel, are inherently racist. Other groups may want to maintain a campaigning stance within the community and regard the involvement which you seek as compromising that position.

CASE STUDY *What an ethnic minority development worker can achieve*

Haringey Health Authority was one of the first to appoint an ethnic minorities development worker. The brief was wide, covering equal opportunities in employment as well as developing ways of making services more responsive to the needs of black and ethnic minority users. We focus here on how the worker has tried to involve black and ethnic minority groups in planning services and on some of the factors that influence the success or failure of such posts.

The post was designed to maximise influence within the management structure. It is on a comparatively high grade (scale 18) and is accountable to the district general manager. The overall direction of her work is the responsibility of a steering group including health authority members and community representatives as well as other chief officers in the authority. At various times suggestions were made that the development worker should be attached to community medicine or the personnel department, but the worker felt that an independent but central position for the post was essential, to avoid being marginalised.

Much of the work, at first, has been in developing good relationships with local black and ethnic minority groups. This was initially a slow process and she encountered cynicism, suspicion and even hostility. When her letters were not answered she phoned to arrange personal visits to groups (rather than expecting them to visit health authority offices). Although a number of groups felt they did not wish to become involved with what they saw as an inherently racist bureaucracy, others were cautiously willing to cooperate.

The worker put considerable time into following up requests for information and developing good personal relationships. She also invested effort in encouraging managers to visit groups themselves. Managers were often anxious about this yet were usually pleasantly surprised to find that groups were not as aggressive or as unsympathetic to the health services' problems as they had supposed. The development worker briefed health authority staff before meetings, about the need to avoid being defensive in the face of criticism and to avoid adopting a 'colour blind' approach to improving services.

Discussions with community groups led to the decision to focus largely on two areas - psychiatric services and services for elderly people. Initially, the development worker assumed that it would be appropriate to involve black and ethnic minority community representatives in the two established joint planning teams on mental health and on services for elderly people. However, having attended them herself she felt that this would be difficult and inappropriate. Instead, the planning teams set up subgroups to develop policies for the main group. The black and ethnic minorities mental health forum has representatives from social services, health service management, probation, medical and nursing interests, as well as representatives from local black and ethnic minority groups, the CHC and the community relations council. The chair is the chair of the joint planning team for mental health services and other members sit on both committees.

The group has been meeting for 15 months and there is a high and regular attendance (if a community representative misses a meeting they are always phoned to find out why) and there is a good group feeling. This has perhaps been helped by the fact that the group's activities have so far been largely task-oriented although there is a move to spend more time developing policies for the planning team.

Major activities so far include:

1. The introduction of ethnic monitoring of service users. This took time to get off the ground because of problems with junior doctors, over confidentiality and form filling, eventually overcome by the energetic intervention of one of the consultants.
2. Preparing information on how to use services and what to expect from them. A student has been working on this but it is likely that professional help will be needed to complete it.
3. An advocacy project in the community is being set up.
4. A multi-ethnic helpline offering information and advice in a wide range of languages is in the process of being established.
5. Jointly developing policy on section 136 of the Mental Health Act and the use of hospitals as a 'place of safety' between the health authority, social services and the local police.

Work with services for elderly people has proved slower. The planning team felt the need to supplement the community representatives' view of what was needed and commissioned a survey of local needs on which to base future policy.

This has taken a considerable amount of time. Money had to be raised, eight interviewers appointed and 256 interviews carried out. The analysis and writing up was undertaken by the development worker and the district health education officer - both busy people who have found difficulty in making time for it, and this has caused further delays. The survey found little that was news and largely reinforced the views originally put forward by the community representatives. The most common issues mentioned were the need for access to appropriate religious ministers, difficulties over language and communications, inadequate provision for diet, and confusion between the role of the health authority and social services. The group is only now beginning to develop policies, a process that has been delayed in awaiting the outcome of the survey.

The work outlined above highlights several lessons:

1 The appointment of a black and ethnic minority development worker can be an excuse for other officers to feel that they do not have to deal with the 'problem' of making services more responsive because it is the responsibility of a 'specialist' worker. It is therefore crucial to establish management and support structures which legitimate the changes being recommended by the worker, and which help to make them everybody's responsibility. For this to work effectively, the location of the worker within the organisational structure is crucial. In Haringey, the worker had considerable access to power and decision-making structures, linked to active support from the DGM and health authority. She was therefore able to ensure that service managers had as high a stake in making changes as she did.

2 Working for changes such as these is a slow process. This needs to be acknowledged by both the health authority and the community organisations in order to minimise frustration and maintain support for the work. This may rely heavily on the interpersonal skills of the development worker.

3 The background of the Haringey worker as a community worker was clearly helpful, and for jobs such as these, community work skills may be more important than traditional management skills. On the other hand, there is a danger that the worker may fall between two opposing 'camps', never quite matching the expectations of either of them. Again this can be countered if well-designed support and management structures are established and regular (and frank) steering/progress meetings are held.

4 Workers such as these, together with their steering committees, need to recognise the considerable anxiety that managers and staff may have about working with community groups, and develop ways of overcoming these. Similarly there also needs to be recognition that people within the service are usually unfamiliar with the ways of working of community groups and may become frustrated when their letters go unanswered or when they expect unrealistically speedy responses. Contact with local groups needs to be well-planned and co-ordinated to avoid repetitious exercises and overstretching of their limited resources.

5 The survey of the needs of elderly people from ethnic minority groups did not find much that was new and one cynical interpretation of this was that the whole exercise was a very successful delaying tactic.

This case study is described in more detail in Kalsi N, Constantinides P. *Working towards racial equality - Haringey experience*. King's Fund Primary Health Care Group and Haringey Health Authority. 1989.

SURVEYS - limits and potential

In some circles 'taking users into account' is synonymous with carrying out a survey. In our view surveys do have a role but a limited one. Ideally, surveys should simply be considered as one tool in the kit and should only be embarked on after considering the alternatives.

Gathering information about the needs of users and potential users is an important part of most exercises in 'consumerism', and is often seen as a project in its own right. Although there are many ways of obtaining information, there is a widespread assumption that local surveys are the 'best' or indeed the only reliable way.

Considerable time, money and effort is devoted to local surveys and often ideas for service changes are greeted by the response that resources will not be available until 'need' has been demonstrated by a survey. Yet in an interesting study by Jones et al that looks at more than 200 surveys, the overall picture is of a vast amount of effort being expended to depressingly little effect on policy (1). To be an effective source of information on which to base policy, a survey must satisfy *all* of the following criteria:

1 It must ask a question to which the answer is not known.

2 Easier ways of gathering the information should have been considered and rejected.

3 It must be clear that different survey results will have different policy implications.

4 There must be a serious prospect of making the policy changes implied by the answers.

5 The survey must be well-designed, its methodology sound, and the whole exercise properly executed - to ensure reliable results.

6 Sufficient resources must be allocated for analysis and writing up, and for production and dissemination of results.

Although these points may be obvious, a depressingly small number of surveys satisfy them. We will not discuss them in detail, but will make a few comments about each to indicate the sort of problems that arise.

1 *It must ask a question to which the answer is not known.*

Endless surveys are conducted to establish that, yes, a particular disadvantaged group in this district is unaware of services in exactly the same way as has been demonstrated elsewhere - that people without cars find it difficult to reach distant hospitals and so on. Such surveys contribute almost nothing to local knowledge. There is of course the potential for using the results to fuel a shock-horror local scandal. However, this is time-consuming and expensive and if creating political effect is the only aim of a survey, it needs serious questioning.

A closely-related use of surveys is in response to the often-asked question 'but how do we know it's true here?'. Significantly, this point is often made by those who oppose the policy implications even when shown that a particular issue is locally relevant. There are many other ways of making reliable estimates about the local situation, which will be discussed below (see Section 7). What is clear is that carrying out unnecessary surveys can cause delay and diversion of resources, as the case study on p 43 indicates.

2 *Easier ways of gathering the information should have been considered and rejected.*

Make sure that the information you want is not more easily available elsewhere - by extrapolation from national figures, for example, or from local voluntary groups, such as Age Concern.

3 *It must be clear that different survey results will have different policy implications.*

Sometimes surveys are carried out when it is hard to see how the result would affect policy. For example, plans to provide an extra session to a underprovided chiropody service do not require a survey to identify 'need' in order to justify them. On a similar point, surveys which allow for, or assume, only one potential outcome (which conveniently mirrors current proposals) have only propaganda value. When planning surveys it is vital to think through the ways in which the possible results would have policy implications.

4 *There must be a serious prospect of making changes.*

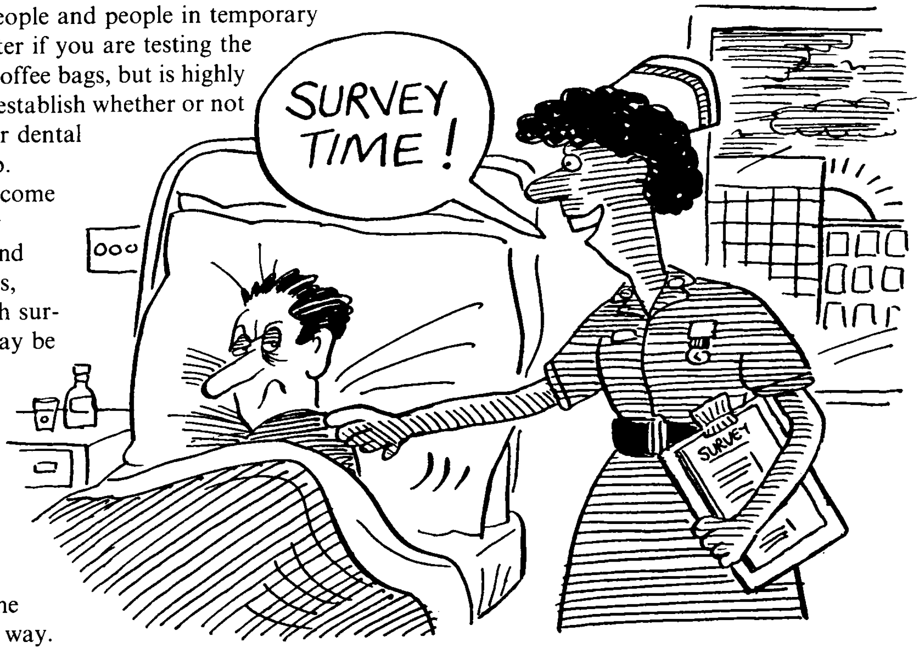
Discovering things that cannot be changed is a waste of time and money. Jones et al found that virtually every hospital in-patient survey asked a question of waking times (thus also contravening point 1) and virtually none made any serious proposals for dealing with this seemingly intractable problem. Many surveys cannot resist asking questions on housing, social services, poverty and other interesting topics, the answers to which are often totally neglected in the conclusions of the report as being outside its remit. Similarly, there is little point in finding out that many old people wish bath attendants would cut their toenails unless you are prepared to discuss the result seriously.

5 *The survey must be well-designed, its methodology sound, and the whole exercise properly executed.*

Survey methods are covered in detail in many books (2). A look at some of them will reveal that survey methodology is a highly technical subject which many people have made into a career. Enthusiastic amateurism is not enough.

Inadequate methodology often makes it impossible to draw legitimate conclusions. There is no one right way to do surveys - the acceptable margin of error depends on what it is you are trying to find out. For example, the fact that telephone surveys tend to under-represent poor people, deaf people and people in temporary accommodation may not matter if you are testing the market for double-glazing or coffee bags, but is highly significant if you are trying to establish whether or not the introduction of charges for dental checkups would affect take-up.

Techniques needed to overcome factors that can distort survey results, can be sophisticated and time-consuming and, it follows, costly. For simple local health surveys, some of the problems may be insuperable. There is considerable evidence, for instance, that the age, sex, class, race and perceived authority of the interviewer will influence answers. When interviews are conducted by volunteers it is hard to make sure that everyone asks the questions in the same way.



Also people in vulnerable situations, such as in-patients or those who see 'the authorities' more as a threat than a source of support, may feel obliged to give the 'right' answers, despite assurances of confidentiality given by trained interviewers.

Sampling too is not without its difficulties. It may be necessary to survey an enormous sample in order to get significant information about a relatively small group in the population that nevertheless has real, often unmet, needs for services (people not registered with GPs for example). Many sampling techniques under-represent disadvantaged groups, so that talking to people who use a service gives no picture of what under-users think.

Traditional contact methods, such as postal surveys, door-to-door contact and telephone surveys miss some people altogether, including those whose first language is not English, people who are too frightened or frail to open the door, people with learning disabilities, or literacy problems, people who are depressed, travellers or homeless families living in bed and breakfast hotels. Yet it is precisely these groups of people who often have atypical or special service needs. Failing to gather their opinions and suggestions must cast serious doubt upon the value of the results for service planning.

Finally, even if surveyors have great confidence in their work, they may find that politically unacceptable results will cause opponents to quibble over flaws in the methodology and execution. This even happens when surveys have been conducted by professionals - so beware!

6 *Sufficient resources must be allocated for analysis and writing up, and for production and dissemination of results.*

Analysis and writing up are major parts of surveying and the amount of work involved is often not recognised. It is not uncommon for interviewers to be employed but analysis and write-up to be left to some permanent and busy member of staff who was involved in suggesting the project, with a little help from computing staff.

This is usually a recipe for disaster. Bad planning can mean that even where pilot questionnaires or surveys are conducted, the enthusiasm to get started can prevent discussion on some of the potentially interesting outcomes. Often, when new information starts to emerge it becomes clear that other questions ought to have been asked, whereas some of the existing ones could have been jettisoned. For example, a survey might reveal that 10 percent of people over 70 years old have had chiropody home visits, but there may not be information about whether this was NHS or private. There may, on the other hand, be mile-long print-outs about which people use/do not use, like/do not like, eat/do not eat their meals-on-wheels; information which is probably available anyway in routine records.

The number of surveys that never get written up is not known but must be considerable. It is not uncommon to hear that the write-up is delayed beyond the time when it can usefully influence decisions, or that it never gets beyond a draft which has not thought seriously about conclusions. Sometimes the only outcome is a forlorn appeal for more money to complete the analysis.

The production and dissemination of a report is the final stage of a survey, without which the interviewing and analysis are wasted. Realistic resources and timetabling for all stages are therefore essential for the success of a survey.

The reputation of surveys as an easy way of taking account of the consumer's viewpoint is misplaced. The following two brief examples confirm this:

CASE STUDY: *a survey of the aftercare of elderly people discharged from hospital.*

East Birmingham Community Health Council was aware of the problems elderly people faced in getting the services they needed - particularly just after discharge from hospital. It decided to investigate the extent of unmet aftercare needs of elderly people in East Birmingham, and to make recommendations for planning and provision of services (3). The work was funded by a grant of £4,300 from West Midlands Regional Health Authority.

The professional standard of the survey the CHC produced is above average. It had two paid staff, academic and expert advisers, and considerable cooperation from the regional computing department. In the report the author courageously included a short section on the methodological problems that arose.

First aims were not well-defined, particularly with respect to how they would relate to policy. Instead, everything of interest to do with aftercare was included. This resulted in a very long questionnaire. Some frail interviewees only answered the beginning, not necessarily the most useful section.

Despite the pilot, faults in procedures were missed. The letter requesting an interview did not say that the interview could be with a friend or relative if the person discharged would be unable to manage it, and telephone contacts only thought of mentioning this after a while, so it seems likely that frail and confused people were under-represented. Because interviewing was seen as the major task, the project supervisor's job involved spending most time on this, and it was left to volunteers to do the administration, trouble-shooting and write-up.

Because of pressure of time, the training of interviewers missed a number of important points. It was found that to make sense of the answers interviewers needed considerable knowledge of health and social service personnel as well as a familiarity with a range of medical conditions and the treatment and aids people were receiving. Later interviews were more useful than early ones.

A major factor that was initially underestimated was the impact that such an interview would have on the interviewee. Despite careful explanation, many elderly people may have felt that they had communicated their needs to someone in authority. As the author says, were they left saying 'someone came round asking what was needed after I was in hospital, but we never heard anything...'? In fact, interviewers did get involved in referring cases, and also in giving out a lot of information, which they found considerably facilitated the rest of the interview but which obviously took time. In retrospect they felt they should have developed a policy on how involved they were prepared to become and probably should have done more than they did.

The combination of the survey's wide remit and the complexity of issues involved meant that analysis was very complicated, but little thought was given to this until after the data was collected. A follow up interview was carried out but not analysed at all. The length and design of the questionnaire also meant that the standard computing package could not be used on it, and a special programme had to be written.

A final point was that when the hidden expenses (eg. computer services, unpaid time from research steering group) were allowed for, the survey cost around twice its original budget. And, to repeat the point, this survey was better financed, had more experienced involvement and support, and was more competently carried out than many.

CASE STUDY: *North West Thames - Critical Incident Interview Techniques*

North West Thames Regional Health Authority co-ordinated a programme of six pilot projects designed to test different approaches to 'managing customer relations'. As part of the preparation for the proposed work a 'snapshot' was taken of user views in each of the services under study. It was an attempt to find out which bits of the service annoyed people, which things would make it acceptable or good, and what kind of expectations people had about different aspects of their use of the service.

A total of 572 patients were interviewed using Critical Incidents Interview Techniques, and the method, findings and consequent recommendations are written up in three volumes (4-6).

The interviewers were trained in the techniques to be used in the study, and included unit staff, consultants from the regional management and organisation development division and researchers from the industrial training research unit. They conducted interviews in parts of the service in the six pilot districts that had been selected by unit general managers as having the greatest volume of contact with 'customers' i.e mainly accident and emergency and out-patient departments.

The interviewers collected information on the presence (or absence) of good practice, namely those events which had a significant effect on the patient. These include, for example: the ability (or not) to choose appointment times; the provision (or not) of specific information about the hospital's location, waiting lists etc; the helpfulness and politnesss (or indifference/rudeness) of reception staff.

Information was also collected about irritants - incidents which were annoying but which did not directly affect obtaining advice and/or treatment. Irritants included things like: insufficient chairs in the waiting rooms; a waiting area which is too hot/cold/noisy/dirty/drab; lack of parking facilities; poor public transport; unpleasant toilets.

The region made recommendations about how the findings should be used. It suggested that after the taking of 'snapshots' managerial action should be based on a comprehensive customer relations policy, stressing that such surveys are not a discrete exercise, rather a means to an end. It also recommended that managers concentrate their efforts on the concerns identified by users during interviews, arguing that 'snapshots demonstrate that customer relations is well within (managers') control'. The findings yielded a checklist of good practice against which service delivery could be measured in the future.

The checklist includes good practice in relation to:

- making appointments
- information about the hospital/unit
- reception
- the consultation/treatment
- providing information about the consultation/treatment
- waiting for the appointment.

The responses by managers included the appointment of an out-patient department manager, the establishment of quality circles, staff training, consultant seminars, more public relations activity.

This case study illustrates how a well-planned and executed survey can be used as part of a more general customer relations strategy. The findings of this fairly extensive piece of research clearly showed that responding to irritants was within the manager's sphere of influence. There are however a number of other issues which this survey raises but which are not dealt with explicitly in the reports.

1 *No news*

To make services better suited to users' needs, you need to know what they want, certainly. North West Thames Regional Health Authority found that patients need to understand what is happening, they need to be treated with respect, they need to see fairness in the way that systems are applied, and they want to feel satisfied with the outcome of the consultation/treatment. The survey also showed that people do not like waiting for a long period of time on uncomfortable seats in dark, cold, drab corridors with no facilities for children, elusive toilet facilities with no loo paper, and the prospect of a long and complicated journey home ahead of them.

In short, there were no surprises. The principal findings mirrored the findings of many surveys previously conducted by community health councils, out-patient departments and accident and emergency departments.

2 *Missing people*

Surveys of a 'captive' audience necessarily exclude people who have not yet managed to reach the services they need. Blocks to receiving treatment and care do not always emerge from questionnaires and patient surveys but nevertheless require management action. For example, people might find it difficult or impossible to reach the service because they lack access to transport, or because they are not registered with a GP, or because their first language is not English. Managers need to seek the views and experiences of people who are disadvantaged - doubly in many cases because they have no opportunities for making known their views. It may then be possible to begin to plan changes to services in order to make them more accessible for all groups of service users.

3 *The nature of change*

Survey questions sometimes reflect health workers' and managers' perceptions of things that might be changed. These tend to be problems that can, in theory, be successfully tackled by them - such as provision of more information, more chairs, better decoration. These are often 'cosmetic' changes, though their impact should not be underestimated.

On the other hand, too much of an emphasis on these types of changes means that questions are not asked about the patient's satisfaction with treatment and care. It also carries the risk that the management response to any identified problems which may have more complicated repercussions (eg. patients disliking the attendance of medical students) may be to change the patient to fit the system rather than the other way round. In this example, this would involve providing 'educational' literature persuading patients that it is in everybody's interest to allow students full access to all investigations and examinations.

4 *Wider implications*
Asking patients what they think about a particular service may have wider repercussions. For example, a survey in the out-patients department may reveal problems with the ambulance service, or the pathology labs, or with community health services. It is a good idea to open negotiations with other departments and units at the time that the survey/questionnaire is piloted, and to try to win commitment to making changes where necessary.

Surveys often have other uses than the explicit one of gathering information which will help formulate policy. One common use is to provide ammunition that is difficult to ignore in a local argument. Even if the results could have been arrived at with equal or greater reliability by other means, a survey of the actual people affected, with its connotations of neutral scientific respectability, may have greater political impact. A successful survey can also enhance the credibility and sense of purpose of, say, a local agency or small group of staff as well as providing them with an interesting learning experience. And the process of carrying out a survey may inform both interviewers and interviewees about an issue and do the groundwork for a campaign.

There is nothing wrong with using surveys for public relations, for commitment-building, or establishing credibility, but if this is the main role of the survey, its use needs to be assessed against other means of achieving the same ends. The amount of work involved should be a major consideration. Sometimes a small, quick survey can be useful. For example, during the establishment of the Haringey Advisory Group on Alcohol (see p 55), a short postal questionnaire was sent to local magistrates, police, social workers, accident and emergency departments etc. asking about the help they could offer to problem drinkers. The findings showed that people were either referred to Alcoholics Anonymous or a hospital unit at the other side of London. The survey uncovered considerable concern and frustration about the absence of local services which could then be used to good political effect. Such surveys can also provide a way of locating people with a particular interest who can then be co-opted to further action.

FINDING OUT IN OTHER WAYS

Finding out what other people have done is often extremely helpful in deciding whether to conduct a survey. This applies both to the *processes* of designing and implementing a survey and to the *results* of other people's work. It is often possible to extrapolate from national data or local information from other districts. There are many questions about the applicability of such results to other locations but this can often be an inappropriate worry. For example, age structures for Bournemouth (desirable retirement site) are likely to be different from those for Peterlee (new town). Yet findings from information-gathering exercises about access to services for elderly people are likely to reveal some *general* lessons which will have applicability in other settings.

On the other hand, if there are grounds for concern about non-applicability of someone else's survey, instead of conducting yet another survey, it may be more efficient to build on existing experience by writing a paper sorting out the locally and nationally relevant findings and adjusting the picture using local census data etc. If there are no skills in the district to carry out this sort of analysis, it is unlikely that new surveys will be managed effectively either.

Obviously there are many issues on which no appropriate research has been carried out, for example, the access implications of moving a service to a different hospital. A few sessions with a bus-map and a watch, discussion with tenants' associations, pensioners' groups, or other particularly affected groups, may produce quite enough information as well as highlighting particular points (for example the inaccessibility of a particular estate or the slowness of a bus route on football match days) that would probably be missed by a survey.

Finding out what has already been surveyed is not always easy, since, as we have seen, many surveys are incompletely written up and/or inadequately distributed. There are however a number of sources which need to be investigated to avoid reinventing the wheel.

The Quality Assurance Information Service (QAIS) based at the King's Fund Centre provides information about current work, strategies and individual activities in quality assurance in health care in the UK. Part of the service includes the collation of information on initiatives in 'consumer satisfaction' and QAIS provides a bibliography with descriptive abstracts of surveys, research and other approaches.

There are other sources of collated material on health surveys. For example, research done in the Academic Department of Community Medicine at Edinburgh University looked at a range of different surveys, and their findings have been published in *Consumer Feedback for the NHS* (1). Similarly, Ann Cartwright reviews some of the ways in which surveys have been used in health and health care and looks in detail at more than 50 studies (7). The Centre for Health Economics at York University carried out a study of customer relations work and feedback surveys in health authorities in England and Wales. Their package of publications contains invaluable material on what has already been done, together with guidance on how to conduct effective surveys (8-10).

At a more local level, district or regional statisticians or community physicians may know of relevant work in other districts. They may have helped design or analyse surveys in neighbouring districts.

Within the district, district information services may know about past surveys and their impact. Sometimes departments of community medicine employ research staff to do mini surveys which may not be as well disseminated as large scale work. Quality assurance departments may also have banks of information about local and national survey work. CHCs also have a history of conducting surveys of patients and users, many of them done as a joint exercise with the health authority. Find out from the CHC who and what has been surveyed in the past, and whether or not things improved as a result.

Finally, a very practical way of finding out whether the wheel is being reinvented is to publicise widely any plans for a survey. If it has been done before, you might well hear about it from an indignant predecessor.

Complaints systems are another source of information - specifically about problems faced by users. Some health authorities have begun to use the information which they collect systmatically about user complaints to monitor levels of dissatisfaction with services. This must be seen as a very reactive way of testing the responsiveness of services since often things must have been really bad before a complaint is made.

Having said that, the information about common complaints - together with an outline of how they were dealt with - can add to a picture of users' views gathered by other methods.

Surveys have become synonymous with NHS consumerism, and there is no doubt that they form the bulk of the work that is currently being done to feed in user views to service planning. We have attempted to temper the enthusiasm for surveys by pointing out how hard it is to do a good one. However well-executed, surveys need to be viewed in the context of a range of other approaches for enhancing the contribution of users. These are discussed in the next section.

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Section 7

BEYOND SURVEYS

Doing a survey is only one of a number of ways of finding out about users' needs and preferences. In this final section, we look at other ways of building up a strategy for making services more responsive to those who use them.

A number of attempts have been made to classify the various ways of involving users in planning health services. Maxwell and Weaver identify a spectrum, ranging from consumer protection, through open managerial decision-making, full management participation by public representatives, to heightened individual and communal responsibility and power (1). There are obviously other ways of grouping the various initiatives, such as their origin (e.g community, management, members), or whether they represent direct or indirect action (2).

In this chapter we have arranged different approaches to making services more responsive to users in a way which seems to be practical for managers - beginning with formal structures, followed by some of the informal ways of making contact and gathering user perceptions. Finally, there is a brief discussion about approaches which are specifically designed to equip users with enough power to get the most out of the NHS.

FORMAL STRUCTURES FOR USERS

For managers and planners in the NHS, talking formally to service users and/or their representatives is nothing new. Guidelines on formal consultation have emanated from the DHSS from time to time (3-5). The 1973 Health Services Act established CHCs to represent the user's voice. There are also recommendations about voluntary organisations being represented on joint planning committees (6). Local maternity services liaison committees and some health authorities have established other types of user forums.

More recently, users have become involved in the planning and delivery of health care through other locally established machinery. Some operate at 'patch' level, such as the Lambeth local advisory groups (see later in this section), or the Pimlico Patch Committee (7).

Others focus on a particular care group (e.g mental health (8), or an issue relevant throughout a particular unit, such as race).

The *structure* of these groups also varies enormously. Advisory groups or planning sub-committees may be set up to feed user views into unit or care group management. Alternatively, users can be co-opted on to existing management or planning groups either as individuals or as community group representatives.

Talking formally with users and their representatives is a way for managers to 'involve' users but this does not mean that it is the best way nor the easiest to do well. User representatives on formal committees often experience frustration and confusion (see p 34). The following points may help managers make successful contacts.

Support representatives

User representatives on formal committees are likely to need support if their contribution is to be maximised. The health authority must accept that ensuring 'representativeness' is not the sole responsibility of the representative. If managers become familiar with their local community's make-up and establish good selection mechanisms, the representativeness of the user voice might improve. 'New blood' will also be available if longstanding representatives have become 'tamed' and the committee needs revitalising. On the other hand, time and effort need to be invested to help new members to assimilate the background knowledge necessary before participation is worthwhile.

In other circumstances, a different kind of support is needed. Over-reliance on one or two key representatives is often a danger. For example, an articulate elderly Afro-Caribbean woman with knowledge and experience of community health services and ties with local groups could find herself to be overwhelmingly in demand. Managers need to recognise this and think of ways of helping key individuals cope with their commitments, such as offering personal briefing sessions instead of sending out inch-thick agenda papers. There are other reasons for providing resources and guidance for representatives. *Not* giving support can sometimes be perceived as a way of marginalising their contribution; whereas helping representatives to strengthen their role will help to avoid accusations of tokenism.

Invest long-term

In Section 3 we stressed the importance of clarifying the aims of a particular forum and the sort of tasks likely to be covered. This also helps in judging whether or not existing formal consultation mechanisms are working well. For example, because of the time which needs to be invested in them in order for them to work effectively, participating planning mechanisms (such as joint planning teams or local advisory groups) ought to be relatively long-term exercises with some continuity of subject matter. In this way they can become the central reference point for other consultation and discussion exercises which may be arranged as 'one-offs'.

Be honest

One of the common criticisms of formal talks between statutory bodies and users and their representatives, is that the consultation is merely a token exercise and that sometimes decisions have already been taken, or are even well on the way to being implemented. If sometimes you engage in consultation purely as a public relations exercise it is unrealistic to expect your protestations of commitment to be believed on other occasions.

Establish ground rules

The status and powers of advisory groups and other forums need to be carefully thought out and discussed with user representatives. Such groups need to have formally established ties with key decision-makers and managers. Otherwise responsibility for action may be conveniently deferred indefinitely. To avoid this, consider naming a health authority manager as facilitator for the group's decisions. Another complementary way is to have senior managers as members of the forum itself so that decisions are jointly derived and there is no room for out-manoeuvring unpopular decisions on the grounds that they are unworkable.

CASE STUDY: *West Lambeth local advisory groups*

In 1985 West Lambeth Health Authority received a paper which set out a constitution for local advisory groups (9). It proposed that local advisory groups (LAGs) would be attached to a number of new priority care developments in the community and that half of their membership would be local people. The other half would be health and social service staff and GPs. The health authority accepted the paper.

The working group behind the paper* had consulted informally with district units, care group planning teams, the CHC and various local user groups. It became clear that LAGs should only be established after active community development work and wider consultation with local people such as through public meetings.

Constitution of LAGs

Each LAG was to have a constitution which would lay down:

- **how the representative membership would be sought**
- **frequency of meetings**
- **obligations to the health authority**
- **obligations to the local community**
- **that public agenda and minutes would be circulated.**

LAGs would have three groups of members:

- **local people (individuals)**
- **local health and social service workers and GPs**
- **local voluntary and community groups.**

The ratio of statutory to non-statutory membership would be half and half. The chair of the LAG would be elected from within the LAG itself, and would be a local person, not a staff member. One of the staff members would be secretary to the LAG.

The structure allowed 'courts of appeal' right up to the health authority. For example, if local management failed to respond to advice from the LAG, the community members would then appeal to the relevant unit and so on, up through DMT to the health authority. If staff representatives were unhappy about LAG advice (for instance, if it was regarded as unworkable or against professional ethics, or was a managerial rather than a policy matter), then they would appeal to the managers of the relevant unit.

Using Inner City Partnership money, community development workers were employed to begin the groundwork necessary for getting LAGs established. They made contact with tenants associations and other groups, and individuals in the community were encouraged to see the health centres as a resource based for them.

LAGs were established in some of the new centres developing priority care services, and began to carve out their tasks and roles.

The 1984 Reorganisation 'hiccup'

The Griffiths proposals for reorganisation of NHS management came in 1984 hard on the heels of the establishment of the LAGs. This had a number of implications for the progress of LAGs and community development.

First, people in the health authority who had been instrumental in getting LAGs off the ground and maintaining their momentum left the district. There is now no-one working for the health authority either with an overview of the LAG scheme or with the power and enthusiasm to maintain their profile. This has meant that where LAGs exist they have developed different styles and constituencies, and vary in the amount of influence they have. For example, the community care centre in West Lambeth has a CAG - a Centre Advisory Group. Although good links between the centre and local people and groups is fostered and maintained, the focus for the work of the CAG is firmly attached to the institution. The work of the

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* district medical officer, planning officer, community unit administrator, CHC secretary and director of nursing services.

CAG is discussed in more detail on p 7.

Secondly, the introduction of the general management 'culture' has had a number of implications for the status and role of LAGs in West Lambeth. The pressure for quick decisions and speedy results has been damaging to the culture of user participation and has downgraded the importance of community development. Some of the people we have interviewed in connection with LAGs felt that they were receiving much less support than in the past.

The restructuring of management units and planning systems following the introduction of general management had an impact on the relative power of LAGs. The original idea was for LAGs to feed suggestions into the relevant joint care planning teams. After the reorganisation, the status of JCPTs changed, in practice at least, in that general managers had power enough to make changes to the services they managed. The management structures had changed, seemingly without acknowledgement of a system of user involvement that had been set up to operate in a different power structure.

The LAGs in West Lambeth highlight a number of important issues:

1 LAGs were the brainchild of keen enthusiasts at a high level in the authority (plus some outsiders). This commitment did not necessarily exist at other levels in the organisation, and so when the key actors moved on, the status and position of LAGs was bound to change.

The dynamic individual(s) syndrome need not necessarily mean that sustainability is a problem - provided that there is some investment in building commitment for the approach and in thinking through the implications. It is also crucial to write things down for future postholders - not simply operational documents, but working documents, drafts, philosophy and rationale.

2 The LAGs, as their name implies, are advisory. This term means different things to different people and when LAGs were introduced some community groups with long histories of involvement in NHS decision-making actually felt that their power had been reduced. Other groups were unclear and uncomfortable about their advisory function and the LAG might have benefited from more open discussion about what each 'side' could and should expect from the other.

3 The aim was to ensure the representativeness of the community representatives through accompanying community development work. The community development workers in West Lambeth worked hard to make links with the local community and to make sure that minority groups were not squeezed out.

This is a long, slow process and in the early stages 'community representation' may actually be a misnomer. So long as this is acknowledged and active attempts are made to make better links, this need not be a paralysing concern.

4 Following from this, continued community development work is essential, not only for generating candidates for election to the LAG, but also for sustaining interest and involvement. Representatives and individuals in the community need to feel that being involved is worth their while. They need to feel powerful and this is partly aided by providing information about, and help finding their way around the NHS bureaucracy, and partly by making sure that appropriate responses are made to issues raised by local people. Community development workers have a significant part to play in empowering service users and thus can greatly enhance the impact of participative processes.

5 LAGs have undertaken many different activities. But, they have not slotted as neatly into NHS decision-making as originally envisaged. This may be due to the relatively short time they have been in operation. Or it may be because developing strategy is not at present the most appropriate way in which local people can get involved in the running of local health services.

Liaise closely with the CHC

Some CHCs have cultivated valuable links with local groups and individuals in the community and are therefore good potential brokers between managers and users. CHCs are often working towards some response to the current concerns to the local community, and will also have contacts with field staff and managers within the health authority. Some situations will require joint work, and CHCs may be willing to bring together a range of community representatives and viewpoints to feed into discussion and decision-making.

For example, in Haringey Health Authority the CHC had been aware for some time of a gap in provision for problem drinkers and their families. Because of their links with other groups in the community, the CHC was also aware that a residents' association was similarly concerned about the numbers of people with an alcohol problem drinking in their neighbourhood. The chair of the residents' association was anxious not to orchestrate a 'get them off our streets' campaign, but to come forward with positive proposals.

The CHC set up a working party, involving a representative of the residents' association and other interested members. After a series of meetings and visits to other services, a decision was made not to press the statutory services to create a totally new service but to organise the establishment of a voluntary organisation that could begin operating on a small scale very quickly. As a result, the Haringey Advisory Group on Alcohol (HAGA) was established to provide assessment, counselling and, where appropriate, referral for problem drinkers and their families. It liaises with social services and works very closely with the detoxification in-patient service at the local hospital. HAGA also has a training and education role for a wide range of professionals, the general public, school and other groups.

Perhaps the most interesting aspect of this collaboration between voluntary and statutory providers, is that working alongside the workers employed by HAGA are workers from both the health authority and local authority who are seconded for weekly sessions. The health authority has also offered part of an empty hospital to enable HAGA to move from very cramped accommodation in the CHC offices.

Obviously, finding the right balance between statutory and voluntary service-providers and the CHC is complex. In this example, the collaborative work and discussion facilitated by the CHC helped to establish a much needed service. This flexible partnership has continued to operate within the services provided by HAGA, and the group is also looking at ways of incorporating clients' views in the way the service is run. On the other hand, it is important that the health authority does not use involvement in voluntary service provision as a way of avoiding responsibility. It could be argued that acknowledging an obvious need for a service involves a willingness to provide regular funding. Whether or not the largely voluntary funding of HAGA proves appropriate in the long run, the significant issue in this example is that the CHC was a powerful and useful broker between local groups, the voluntary sector and the health authority.

BEYOND THE BOUNDARIES

It is unlikely that formal mechanisms by themselves will yield comprehensive information about user views and preferences, nor should they be relied on to do so. *Even if* every effort is made to make sure that the systems work well and that the two negotiating 'sides' are satisfied that a good working partnership has been established, there is still likely to be a need for other ways of involving people. For example, part of the All Wales Strategy for Mentally Handicapped People (10,11) involved formal consultation with and involvement of parents, carers and voluntary organisations. In one area however, the majority of parents did not respond to invitations to attend local planning workshops. There were a number of very obvious reasons for this - poor public transport and a dispersed population, pressures of caring, lack of credibility in 'the authorities'. In this case other routes were explored, such as several small locally-based meetings and regular progress bulletins.

Similarly, Newcastle District Health Authority was committed to redesigning its services for elderly people with mental illness in accordance with the needs and wishes of the people themselves and their relatives (12). The planning process obviously involved short, medium and long-term horizons and formal planning mechanisms were established to manage the process. The authority decided to supplement the data collected by the formal planning group by contacting 'the public' in one locality by means of a consultation day. The day was well planned with small group work as well as large discussions and yielded new issues which were useful to the policy-makers: that, for instance, services should be local and small-scale; that consultation should be continual; that certain services were seen to be inadequate locally (suggestions were made for improving them). The participants involved in the day had been well-briefed, so the danger of unproductive and angry confrontations was minimised.

Gathering user views *informally* is therefore a useful dipstick which can inform discussion on practical issues of service delivery and influence policy. Within every health district there are a number of local voluntary and community organisations with an enormous collective experience of services, and a good idea of where the main problems lie. There are self-help groups, black and ethnic minority groups, pensioners' clubs, tenants' associations, as well as the CHC. It is worthwhile sharing the task of building up regular contact with networks of local groups. In this way a few key people in the unit will get a better feel about how services are being delivered on the ground. For example, a London community unit manager meets monthly with a local community development project to try to work towards better primary care services (13). The manager uses the group as a source of community intelligence and in return offers a brokerage facility between a range of other community groups and managers, planners and providers of primary health care.

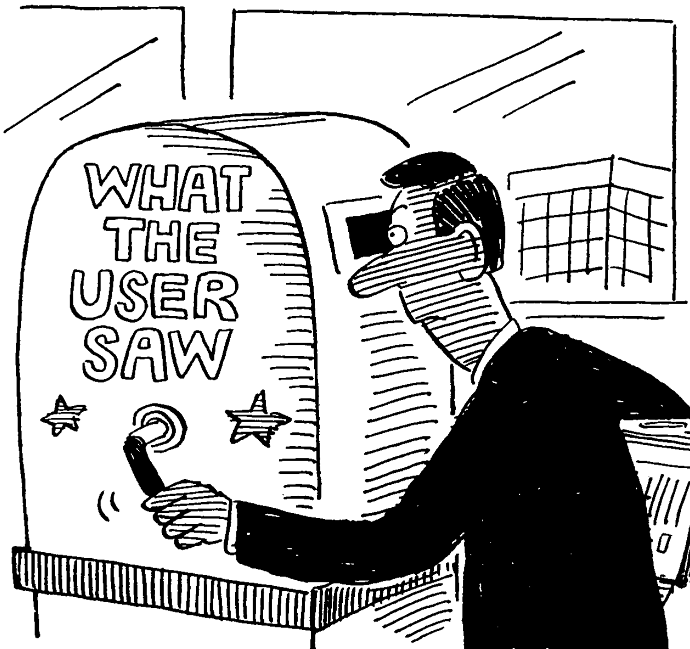
Of course there are problems with the accuracy and representativeness of views emerging from discussions like these. And tackling problems as they are unearthed is not an appropriate planning strategy in the long term. On the other hand, users are in a good position to identify service failures, and troubleshooting improves the credibility of the organisation. The most productive way forward is to view *ad hoc* solutions within a wider context so that they are part of a linked *range* of approaches designed to make services more reponsive. Instead of making the service better for a few people, the lessons learnt from talking informally to users should form a 'working hypothesis' to feed into a wider framework informed by continuous review and evaluation. Having to get everything right at the beginning is less important if there are regular opportunities for locating mistakes and making alterations.

Some informal contacts with users spring from outside the service. For example, the Lambeth Community Care Centre was developed in response to a campaign led by West Lambeth CHC together with local people (14). Other alliances have been forged; some using the CHC umbrella, some independent of it. For example, the Tower Hamlets Health Inquiry incorporated a variety of local groups and individuals who wanted to conduct a review of the appropriateness of local services (15). Gathering information in the form of written data and oral evidence, they attempted to make an independent assessment of how well local health services were being provided. The main thrust of the group was its campaign element and its members had no formal ties to the health authority. However, the report they produced included some starting points for further negotiation and a focus for work towards improvements in the authority.

A USER'S EYE VIEW

A related approach to making services more sensitive to users is to make service providers more directly aware of how users experience their service.

Prior to a recent workshop for managers held at the King's Fund, participants were asked to spend a day gathering user perceptions of their services. A long list of strengths and (mostly) weaknesses of existing services emerged. While containing few surprises, this did locate many important starting points - unhelpful staff attitudes, poor information and communication, lack of flexibility, uncomfortable physical environment and so on. The methods used by the course participants varied but were in the main simple, anecdotal, 'unscientific' and quick ways of gathering usable information. Some managers have formalised this process of getting a user's eye view of services. In South Tees (16) a patient's perception group has been established whereby a unit general manager, a consultant, a CHC secretary, nursing and administration representatives, and the chief works officer attempt to find out about the levels of satisfaction with local service delivery. One of the methods they have adopted is to view the service through the eyes of users, by following patients through a series of contacts with the service, or by talking to them on unit visits.



Birmingham City Council has established the Community Care Special Action Project to create opportunities for people with special needs and their carers to be consulted, feel valued, to have choice, to participate and to be accepted as integral members of the community (17). The project works in a number of ways - including information weeks in neighbourhood offices, consultation meetings with carers, and involving users and carers in planning and the development of policy. But one of the most powerful ways of finding out what it is really like for users is to experience it first hand. The director of the project always spends her overnight stays in hostels and residential care centres (18). She feels that this puts her in a better position to understand more fully the practical, day-to-day hassles, upsets and unordinariness of the lives of people being 'provided for'.

The BMJ runs a series of 'personal views', some of which portray the experiences of doctors 'tasting their own medicine' (19, 20). The intensity of their sudden insight into what it's like to be on the receiving end of services has been powerful enough to change an individual's working practice for life. On the other hand, it's not always clear how these individual experiences can be harnessed to have a more general impact on the way services are delivered.

A more extreme approach, more often adopted by researchers than managers, has been to masquerade as a patient and see what happens. However, this is not to be undertaken lightly - apart from any ethical considerations it is worth remembering the American research team who got themselves admitted as voluntary mental patients and then had considerable difficulty, lasting several weeks for some of them, getting out.

But getting a user's eye view can only ever give one layer of information. It needs to be complemented with other methods.

Supplement your vision

Simple, short-term exercises which make some attempt to follow a patient's footsteps can often offer valuable insights into what sort of things affect patients and users routinely. However they are pointers only and need to be backed by other information sources. This might, for instance, involve wider informal investigation, such as talking to field staff and receptionists, other users and carers.

The user's eye view often matches the results of large scale surveys. This raises two interesting points. First, that surveys sometimes merely confirm what is implicitly or explicitly known. And second, that rough-and-ready information gathered informally can help to identify areas which could usefully be investigated in more depth.

Some pitfalls

The pitfalls in gathering personal views of services also have to be recognised. It would be unwise to interpret one comment as a general problem without somehow confirming with staff and other users that the issue is of wide concern. However, it is also necessary to balance the need for confirmation against the expense and effort of more fomal techniques such as a full-scale survey.

It may be obvious that the way staff respond to, say, a white male middle class hospital administrator who is an in-patient may be very different (even when they do not know who he is) from the way they behave towards a non-English speaking elderly Asian woman. It may be less obvious that the subjective experience of the same treatment can be very different. It may be possible to spend an afternoon sitting in an out-patient clinic and yet miss the fact that an elderly lady nearby spends the whole afternoon in a state of anxiety in case she is waiting in the wrong place, in case she will miss her turn if she is in the loo when her name is called (they've already thought of that one, and call names several times - but she doesn't know that) and worst of all that if the clinic runs late there may be no ambulance to take her home.

Thus although information is valuable, the individuality of both objective and subjective experiences needs to be constantly borne in mind. There is a slight danger that, enthused by the intensity and immediacy of personal experience, managers may feel it is unnecessary to consult further, or find it even harder to accept the legitimacy of experiences that do not accord with their own.

It is likely that the most useful aspect of such exercises is not so much the specific information they reveal but that they offer experience in adopting the patient's orientation, something any manager should be able to do when confronted with many issues of service delivery, and which ought to provide a powerful incentive to make changes.

PATIENT POWER

Although not primarily the subject of this book, one of the most important ways of making services more responsive to users it to give people more control over what happens to them as patients. One of the central themes of the NHS White Paper (21) is the extension of choice for some patients, specifically about *where* to get treatment. Making this a reality will need more than 'shopping lists' of what is available; users will need information and support. Some people have argued that for users to be able to make choices about their health care they will need information about standards, about clinical policies, and about treatment options (22). They will also need support to take them through decision-making, and power to make sure that what they have decided to do actually happens.

There are already a few examples where patients are being offered choices about treatment and care. In community health services these choices may be limited to things such as choosing to have a woman doctor for family planning services, or being able to visit child health clinics in the evenings because of flexible opening times. Some maternity services attempt to accommodate women who have written down their preferences for labour and delivery in an individual birth plan. These attempts to introduce some flexibility and responsiveness into the health service have to be commended, not least because they illustrate that a consumer-led NHS is not an impossibility. However, making them work successfully involves taking on board quite a few complex issues surrounding patient autonomy and patient advocacy - some of which are listed below.

Offer information and power

Offering choice to individual users means offering information and power to exercise their choices. Having a positive attitude towards birth plans does not amount to much if only a small percentage of local, middle-class women (often those attending National Childbirth Trust classes) learn what birth plans are and how they can be written.

It is also important to recognise that some people or groups of people may need help in order to be able to make realistic choices about the services they receive. This can be done by increasing knowledge and confidence through group work or by using advocates and interpreters. One imaginative example of this occurred in an inner city health centre where a group of women with small children were encouraged and supported by a community worker to take a child development course through the Open University.

Advocacy schemes

There is a wealth of written material and practical experience of using advocates, particularly for people with mental illness or learning disabilities and people whose first language is not English (23-25). Such schemes have an effect not only on the individual patient involved. The creation of different patterns of patient/staff interaction has a wide-ranging effect throughout the service. This can be enhanced if staff are given the opportunity to talk about these changes, the challenges they pose to staff roles and the positive things they offer, and also if staff ensure that individual patient choices are not simply left to benefit one or two individuals, but are incorporated into an ongoing evaluation of what the service is offering. A simple example occurs where non-English speaking Asian women being helped by advocates to get what they want from maternity services, make individual requests to see a woman doctor. Even if the women's requests are accommodated, it may be at the expense of a long wait or a wasted visit. By tackling the *issues* which arise from the daily experiences of advocacy, practical ways in which services can be re-shaped inform the management and planning process. Improving the acceptability of services for individual users is much easier if their *collective* experiences are used to reshape services.

The issues surrounding advocacy are manifold and complex, and there are ever-changing debates about the value, management and power of advocacy schemes, such as: whether they should be independently managed or closely bound to the NHS hierarchy; whether advocates should be trained health workers or experienced lay workers. Sometimes problems arise when advocacy schemes are misnamed and in fact do the opposite of what advocacy aims to do by investing effort in communicating staff wishes and directives to the user (26).

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Conclusion

We have tried to demonstrate a *range* of different, but related, activities which can make services more responsive to those who use them. There are exciting opportunities for building a user dimension into everyday planning and management tasks, not least because this is a time of review and change in primary and community health services. And there are new developments and initiatives being established all the time. Many, like building effective links with community groups, are long term, and require continuous effort. On the other hand, some service changes ought to happen quickly, simply because the problems have been known for a long time. These require management action rather than further attempts to find out more about the problem.

It is because of the need to invest time in attempts to make services more responsible to users, that we have concentrated on giving practical help - so that efforts are not wasted. We have also stressed the importance of building commitment and strategies within units (and districts), so that initiatives are not set up to fail in hostile environments. This is also crucial for making sure that initiatives become integrated within the policy and objectives of districts and units, and do not just exist as a series of ad hoc experiments.

Making services more responsive to users of the health service also offers important trade-offs for managers and staff. It makes a lot of sense in terms of planning appropriate and equitable services, can create incentives for positive changes, and provides motivation and satisfaction for staff. But those are not the only reasons for taking it seriously. The NHS is a public service and those managing and providing it have a responsibility for ensuring that users' needs are not secondary to the needs of the organisation. Managers are beginning to accept that users, as individuals and in groups, have rights as well as needs.

To end, we have compiled a list of practical tips which have emerged as the main messages of the book:

Be clear about what you are trying to do
What are you aiming for? Think carefully about the limits of your commitment to making services more responsive to users, as well as the sort of approaches you want to take. Make this clear to users as well as staff.

Acknowledge the need to change
Without a fundamental commitment to making changes happen, it is pointless getting a clearer view of what is needed to improve the quality of health services, and participative exercises are in danger of becoming ends in themselves.

Acknowledge the difficulties
Involving users is a significant management challenge. Much preparation is needed and in community health services in particular there are many different professional views to be considered and users are disparate and difficult to reach.

Think twice before doing a survey
Gathering information about 'what users want' is often seen as the first task for managers who have acknowledged that their service has shortcomings. In our view the usefulness of surveys has been seriously overestimated and other approaches which help to feed in user views need to be considered.

Experiment with participative approaches
It is important to think about ways of involving users rather than just collecting information on user preferences to improve planning decisions. This means empowering users to enable them to collectively determine the pattern and style of service delivery. It is also important to build in safeguards to counter the possibility that disadvantaged groups will be further discriminated against because the chosen methods of participation prevent an effective response from all groups.

Make links with the CHC
CHCs can provide a valuable bridge between the local community and those providing services. They may also be quicker than managers to pick up concerns and problems. Links with the CHC can be a powerful tool for tapping both opinions and resources amongst local people. Strengthening the working relationship may provide a

launching pad for a variety of initiatives that make services more responsive to users.

Invest in preparation and support
Enhancing the responsiveness of a service is likely to be a long, gradual process. Groundwork and continuing support are crucial in order to maintain commitment and credibility amongst both staff and community groups. It is not enough simply to establish structures for user involvement. Support for users and staff must be integral, contact with the community has to be encouraged and resourced, and there has to be commitment to relinquishing some of the power to set agendas and make decisions.

Above all, it is vital that both innovative and 'copied' initiatives are not merely transplanted into an unready and unprepared environment. If we want to leave you with one message after having read this book, it is that making community health services more responsive to users depends upon well-targeted groundwork - both within the organisation and out in the community.

SELECTED FURTHER READING

The articles, books and reports listed over the page have been selected to supplement the reference in the main body of the book. Some of the material has already been referred to in the text, but may also be included here because it covers a wider area or is a key reference. The bibliography is by no means comprehensive, but offers a starting place for further reading on a variety of subjects which broadly relate to making the health service more responsive to the needs of users.

It will also be helpful to find out about initiatives in other parts of the health service and the public sector which re-orientate the service more towards the needs of users. Often these developments are not written up, or if they are remain as internal, unpublished documents. There are a number of ways of finding out about what is happening elsewhere and the information on p 48 may provide useful contacts.

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Allison Quick worked for Haringey Community Health Council for five years before becoming a freelance researcher writing on health issues. Her doctorate from the London Hospital Medical College examined health education and sugar consumption. She is author or co-author of recent reports on the quality of infertility services, health education and people with disabilities, rickets and British Asians, food policy, and commercial influences on health education and medical research.

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