power to the people

THE KEY TO RESPONSIVE SERVICES IN HEALTH & SOCIAL CARE

edited by
Liz Winn

ved in the preparation of this anthology, and many thanks are due to them. A small editorial team based at the King's Fund Centre was responsible for guiding the editor through the production of the book and comprised Barbara Stocking, Pat Gordon, Janice Robinson, Helen Smith, Joan Rush, Andrea Whittaker and Diana Twitchin. Alison Wertheimer and, in the final drafts, Penny Clarkson both did marvellous editing jobs — linking the chapters but at the same time maintaining individual styles. The design and layout of the book has been managed by Jeff Munn at the King's Fund Centre and the enormous word processing task w
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Liz Winn

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

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Foreword

Times change and fashions with them. The emphasis on public participation in the '60s and '70s has switched to a focus on consumerism in the '80s and '90s. There are different approaches and concepts involved, but for health and social services there is still the underlying issue of how to involve users more in the care they receive both at an individual and community level.

This book is an anthology of approaches which are trying, not just to involve users, but to empower them when they come into contact with services.

Our belief at the King's Fund Centre is that there needs to be a shift of power — from providers and professionals to users — if we are to provide the most effective and appropriate services, painful though this shift may be. Within the range of our work in helping to develop health and social care, we have come across a number of examples in different areas. This book brings together some of these examples.

Although the examples are drawn mainly from the NHS, the renegotiated boundaries of service provision arising from the community care White Paper (*Caring for people: community care in the next decade and beyond*) will mean that many of the lessons will be valuable to people involved in providing both health and community care.

This is a book for managers and others who want to take practical steps in health and community care to get closer to users, and to shift the balance of power in their favour. We hope, therefore, that it will provide thought-provoking reading for an audience already redefining their roles in the wake of major policy review in the health and social services.

Barbara Stocking
Director
King's Fund Centre

INTRODUCTION

All the outward signs indicate that consumerism in health services is a major agenda item for managers. Kenneth Clarke has suggested that the aims of the NHS White Paper could be summarised as working towards 'user-friendly services'. Margaret Thatcher has said that the patient's needs must always be paramount [1], and Duncan Nichol, the NHS Chief Executive, has exhorted all authorities to develop a framework for quality based on enhancing patients' experiences [2]. The community care White Paper [3] is peppered with references to consumers, customers and clients. Managers are building patient-orientated objectives into individual performance appraisals, and there is much activity within the patient survey 'industry' [4,5]. The overall message is clear — services should be made more responsive to users. However, the power of the message is diluted by the shortage of detailed guidance about how to turn policy into practical developments. What sort of changes are necessary? How can managers help to reshape the experiences of health service users? Where are the starting points?

Our aim in writing this book was to provide practical help for people working in and around health services who are keen to enhance users' experiences. Gathered together here are a number of developments we have come across in our work which are contributing to more responsive services. By focusing on practicalities, we hope that the book will help to unravel the rhetoric surrounding NHS consumerism.

The examples in the book are drawn from across the country, and cover a range of different services and client groups. The lessons to be drawn however are relevant to *all* users and potential users of health and social care services. Some examples are modest in scale and ambition but nevertheless have had a significant impact on the way services are provided locally. Others represent part of a growing 'user movement' in mental health for example. Some are 'fringe activities' for the NHS. Others, which have been in operation for some time, have benefitted from a new credibility thanks to the current move towards consumer awareness across the public sector.

Despite this diversity, all the initiatives in the book are concerned in some way with shifting the balance of power towards those using services and away from those providing them. Recognising this *imbalance* of power between users and providers is a crucial first step in understanding how to translate policy into practice. In other words, the real challenge of NHS consumerism is to develop ways of empowering and enabling service users.

There are of course many routes to achieving this. Near one end of the spectrum there are brave attempts to share power and responsibility for making decisions about how services should be provided. At the other end is the provision by managers and professionals of basic information about existing services. One of the first things that service providers unearth when they talk to users is a desperate need for more information about when, where and how services are provided. In the first chapter Fedelma Winkler describes the different sorts of information needed by users to help choose the type of service and treatment they need. She highlights the difficulties and conflicts in providing information that genuinely empowers users, and suggests ways it can be done. In Chapter 2 Kathy Meade and Tony Carter focus on health information as a way of empowering older people. They describe how health courses, health shops and health days have created opportunities for gaining access to information as well as structures for mutual support and confidence-building. These activities put users in touch with professionals in new settings with opportunities for more productive discussion about what type of services are needed.

Consultation exercises are a seemingly quick and easy way of getting closer to users. However, successful consultation is notoriously difficult to achieve and in Chapter 3 Martin Bould highlights the lessons learnt from consulting carers in Birmingham, Newcastle-upon-Tyne and the work of the King's Fund Carers Unit, documenting the careful preparation and management of consultation forums that is needed to maximise their usefulness — both to the forum organisers and to carers themselves.

User participation often means attending meetings. In Chapter 4 Andrea Whittaker describes how people with learning difficulties can take an effective part in shaping services — partly by developing and practising meeting skills and understanding bureaucratic procedures. This is only one dimension of the strategy however, and for participation to extend beyond token gestures, effort has to be put into examining established procedures and jargon. Andrea Whittaker advises on ways of making initial contact with potential user representatives and warns of the dangers of loading unrealistic expectations on to them.

In Chapter 5 Liz Winn and Nirveen Chotai describe the efforts of one health authority not only to develop but to maintain links with local black organisations and to support their involvement in black and ethnic minority planning forums. This example demonstrates once again the flexibility needed to work with local voluntary organisations and community groups who mostly operate outside a bureaucratic framework. The authors also discuss why user groups are sometimes unwilling to be drawn in to a formal relationship with service providers.

By no means all attempts to empower users are dependent upon action taken by those working within service providing agencies. Some groups decide that they are more powerful as independent campaigners than as "out-numbered" representatives on a planning committee. Several examples in the book demonstrate the impact of the advocacy movement which empowers users from bases outside health and social care organisations. Kate Butler and Mandy Forrest in Chapter 6 describe how individual users with learning difficulties may be supported in their use of services, as well as in making decisions about them, by citizens' advocates representing their interests. They suggest ways of avoiding conflicts of interest between what is good for the service and professionals, and what would be best from the user's point of view.

In all the examples in the book, where users have combined their experiences and resources, they have created a more powerful challenge to the status quo. Users as groups rather than individuals have greatly enhanced continuity, stamina and experience and the potential to create longer term changes to services. Peter Campbell in Chapter 7 and Colin Gell in Chapter 8 write about their experiences as self advocates, empowered by combining with their peers to influence the shape of mental health services. Peter Campbell describes some of the background to self advocacy and the impetus of collective experience. Colin Gell describes his involvement in the Nottingham patients' council support group and discusses some of the practicalities in keeping up the momentum of user groups.

The activities described in this book show how relatively small-scale developments have begun to have an effect on the way services are delivered to the people using them. Success seems to be heavily dependent on careful planning and groundwork, staff commitment, resources and a readiness to take risks. Where initiatives have succeeded, they also seem to need at least a partial erosion of the service provider monopoly on ideas, debate and decision-making in favour of users. Action that genuinely attempts to empower service users will certainly be challenging. Yet developing user-friendly services without a commitment to enhancing *and* embracing user power amounts to tinkering with compromises.

Liz Winn
May 1990

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Chapter 1

CONSUMERISM AND INFORMATION:

FEDELMA WINKLER

This chapter looks at information needs from the perspective of the health service user. It considers what is available now, and what information would be needed to make informed choice a reality in the health service marketplace. It discusses the obstacles to providing information, the ways in which that information might be made widely available, and what the consequences of this might be for users, professionals, and managers within the health service.

Access, choice, redress, and participation are key components of a consumerism that enables the user to influence the service delivered. The availability of information is essential if those four components are to be meaningful.

WHAT SORT OF INFORMATION?

How do you choose a restaurant? You can find names in the Yellow Pages. You can peer through the window and look at the menu displayed outside. You can use restaurant guides such as Egon Ronay, the Good Food Guide, or AA listings. You can read the restaurant's own publicity, or you can ask friends and neighbours. The guides and listings are compiled in different ways: the restaurant may have paid for its own listing; the Good Food Guide is compiled from customers' comments; and Egon Ronay is based on the reports of its inspectors.

How do you choose a general practitioner? There is no Egon Ronay Guide for prospective patients, no equivalent to the Good Food Guide. You can go and have a look at the building marked 'Surgery'; the plaque outside provides some limited information — usually the names of the doctors who work there, a telephone number, and the surgery's opening hours. Female doctors, by convention, give their first name, so you can determine the gender of the doctors working there. Your local Family Practitioner Committee will have a list (rather like the Yellow Pages) which will give the names and addresses of GPs, whether they are male or female, and whether they provide maternity or family planning services. After that you are on your own.

The local Community Health Council has been called 'the patient's friend'. Friends are usually prepared to offer advice. In the case of CHCs though, whilst some may provide additional information and informal advice, most will claim — incorrectly — that they are not allowed to recommend a doctor and can give no information other that that provided in the FPC listing.

To encourage consumer choice, the government is exhorting general practitioners to issue leaflets describing their services, but in the same way that restaurants may mislead potential customers, because they are seeking to make their services look better than those of their competitors, GPs may also be tempted to put out misleading information.

Choosing a general practitioner is considerably more important than choosing a restaurant, yet we have less information on which to base our choice.

Although there is general political consensus that health service users should have access to information, there is no agreement amongst NHS professionals and managers about what information should be made accessible. Most would agree that information about service availability should be provided, but beyond that, consensus ceases. Even the one clear demand of users that people should have access to what is written about them has not generally been tackled; indeed many professionals and managers actively oppose it.

Users, when asked about their information needs will always indicate that they want more information, but are less clear about exactly what information they would like, and in what form and for what purpose. Professionals on the other hand often have their own views on what patients 'need to know'. For example, the Association of Anaesthetists stated that "Patients going into operating theatres should demand what life-saving equipment is available.... people should insist on the right to know what they are getting". [1] The Association claimed that many theatres (in both public and private sectors) skimped on lifesaving equipment.

The Association's aim of involving the public in their campaign for safer operating theatres was laudable but not very realistic. It assumes that users are reviewing options about elective surgery. More often we enter hospital in pain, or at least feeling unwell. Feeling frightened, probably lying in bed (with professionals standing over you) and perhaps with no clothes on, we are unlikely to feel like checking the hospital's mortality rate or asking for a check on their operating theatre equipment. To be really helpful in making easy choices, information needs to be systematically and routinely compiled by user representatives. It also needs to be readily available and easily accessible to users when they need it.

INFORMATION ON SERVICE AVAILABILITY

Access to services is dependent on users, or the professionals they consult, knowing that the services exist. This section of the chapter looks at information currently provided about service availability.

Family Practitioner Lists

Every post office and library in the country should have a list of general practitioners, dentists and pharmacists in a given area, in alphabetical order and listed by postal district.

Using these lists to choose a doctor or dentist quickly shows the limitations of this system. You may, for example, choose a particular practice because it is near where you live and has a woman doctor, only to find when you go there that it is up a flight of stairs you are unable to climb and that the doctors pass many of their night calls to a deputising service. However, it offers the first ingredient of access by providing the names and addresses of service providers. In this way, the Family Practitioner Committee is ahead of the rest of the health service: there is no equivalent provision of information about hospital services.

Patients' handbooks

An increasing number of hospitals now provide their patients with in-patient handbooks. These are valued by patients, who will be told, for example, what articles of clothing to bring in with them and a telephone number to give to relatives. Some hospitals also provide new out-patients with handbooks or leaflets.

However, these handbooks are mainly provided to ensure that patients comply with the established practices and procedures of the hospital. Brighton Health Authority, much praised for its investment in patient booklets is a case in point. It lists the aims of its booklets as:

- to provide well-written information which will project an image of a well-run professional organisation;
- to establish a corporate identity;
- and to use the literature as an opportunity to encourage feedback from patients.

The booklets were even evaluated to see whether "giving patients this information helps towards making sure that hospital routines and practices are followed and hence it helps in making a stay in hospital as trouble-free in terms of the organisation as possible". The word 'complaint' never appears in the booklets. [2]

Listing services

An increasing number of district health authorities now provide pamphlets which list services or describe particular tests or other medical procedures. A good example of this approach is the A-Z list of community health services produced jointly by Islington DHA's Community and Continuing Care Services and the Community Health Council. It includes all the services provided by the Community Services, together with telephone contact numbers. Readers of the A-Z can find out not only how to contact, say, the sleep disturbance clinic or the bed-wetting service. The A-Z can also inform people about services which they may not even have known existed. Copies of the list, which is clearly and simply written, were distributed with the local free newspaper.

The A-Z gives no guidance as to which services are most likely to meet an individual's needs, nor does it have anything to say about the quality of the services, but that is not its purpose; it was produced to encourage greater use of services.

The most recent examples of these guides are ones on women's health services, produced by Waltham Forest and Wandsworth CHCs. Guides to services are usually distributed through local libraries, health centres, and community organisations.

How useful is this information?

No work has been done on evaluating the usefulness of either the listing leaflets or the guides. It is not known, for example, whether circulating the Islington A-Z led to increased use of particular services.

Leaflets have the benefit of being cheap to produce and can therefore be widely distributed, but unless they are of immediate use will probably be disposed of more or less straight away. Islington recognised this possibility and their A-Z carried a boldly printed message on the front: **'DO NOT THROW THIS LEAFLET AWAY'**.

Guides are more costly to produce. Those covering the whole range of a district's services are mainly used by people whose role is to offer advice and information to others (eg. health visitors). The more narrowly focused guides, looking at a particular problem or service are likely to be of greater use to consumers. For example, a comprehensive guide to maternity services, given to a woman when she becomes pregnant, can enable her to choose and understand services as she goes through her pregnancy and to judge whether those services are providing what they claim to offer. *However, they have the disadvantage of being costly to produce and difficult to update.*

To minimise this problem, it can be tempting to produce information which is so general and unlikely to date as to be of limited use to individuals. Unfortunately many of the leaflets translated into other languages suffer from these shortcomings.

A more fundamental problem with most guides and leaflets is that they describe services as they are theoretically intended to operate or as the professionals would like them to be. Only when armed with advice and information on the quality of services will consumers make informed decisions about their health care.

Some CHCs have begun to produce evaluative guides [3], but because of the lack of agreed criteria for evaluating services, and the inadequacy of formal inspectorates, they fall far short of Egon Ronay or Good Food Guides. Because information of this kind is scarce, they have proved valuable despite their shortcomings. However, the provision of such information should not be dependent on whether or not a CHC decides this is worth doing — it should be a national requirement.

THE INFORMATION NEEDED TO MAKE CHOICES

Choice is central to the market-orientated and competitive NHS of the future, envisaged by the current government and described by one of its advisers, Sir Roy Griffiths:

"Choice depends on information about waiting times, about assessments of hospitals, about medical performance. Choice implies the ability to change doctor more easily and to choose to go to consultants whose waiting times are shorter" [4].

Most districts can supply their GPs with waiting times for out-patients appointments. The general public can also obtain information about hospital waiting lists directly, through the guides produced by the College of Health. However, this information is of limited use without additional comparative data about care, treatment, and clinical policies, and about the competence of NHS staff and likely clinical outcomes. Waiting lists vary widely but for different reasons. For example, a particular consultant or hospital may have short waiting times because they are very efficient. Alternatively it may be because they have a poor reputation or because the consultant is known to have a particular clinical approach to treating certain conditions.

Treatment options

People with a diagnosed condition need the chance to review a range of possible treatments before they are able to opt for a particular course of action. At present though, patients usually have to rely on their GP or the hospital doctor for advice about treatment options. But there are drawbacks to this: doctors may not be aware of all the possible options or may only provide information about the approach they favour. So how else can someone find out about possible treatment approaches? Considerable stamina and the ability to surmount obstacles is needed. They can:

- *Ask for a second opinion.*
  Little information is available on the clinical policies of individual doctors, and so choosing who to ask for a second opinion can be random; it may only re-affirm the first doctor's view [5].
- *Enquire at local or national self-help organisations.*
  Self-help agencies may have considerable information resources but they are not always accessible to enquirers. Agencies may only re-state the conventional medical views if they rely on medical experts to 'legitimise' their information. So it can be hard to choose the 'right' agency.
- *Write to magazine/newspaper advice columns or telephone a 'helpline'.*
  Helplines have become more widely available. It is not always clear whether they are offering information, or counselling, or whether they are promoting a particular product for example, baby food or tampons. There is no control on the setting up of helplines and no independent monitoring of the accuracy of information

offered.

- *Consult medical books written for lay people.*
  These are often written by doctors, and some of them may aim to enhance patient 'compliance' rather than empowering users to make their own choices. Some books written by lay people (e.g Angela Kilmartin on cystitis) [6] have benefitted many people and helped to bring about changes in orthodox treatments.
- *Ask at public or medical school libraries for help or request a literature search at one of the few information resource banks accessible to the public.*
  The lay public does consult specialist literature [7] although this tends to be omitted from discussions on patient information needs. Services such as the Lister Health Information Service (Hertfordshire County Library Service) provide enquirers with both popular and medical/scientific information. The Women's Health Information Resource Centre provides a similar service.

Clinical policies

Differing policies exist for the treatment of many illnesses and many doctors have their preferred treatment options. One of the best known examples is the differing policies for treating cancer of the breast: lumpectomy or mastectomy. Doctors also have differing views on dosages and timescales for administering treatments such as radiotherapy. [8] Getting information on alternative options is often extremely hard to achieve, and only a very determined patient will succeed.

A patient who has done some research and who then goes to their doctor as an informed consumer may have to re-negotiate their position as the traditional doctor-patient relationship with its implied balance of power will be upset. Patients can be branded as 'difficult' or 'unpopular' if they state their own treatment preference.

If, in the future, hospitals contract with districts to undertake specific procedures, agreed 'protocols for care', similar to those operating in the USA, will have to be established. In theory, there is no reason why these should not also be made available to patients — but current practice indicates that this will not be straightforward: for example, some hospitals even refuse to give members of the public the names of its consultants; and elsewhere hospital staff may be frightened of giving out information or are only able to give the 'official line' which may differ from actual practice.

Competence of health service professionals

Despite the fact that, amongst themselves, professionals recognise variations in competence amongst their colleagues, consumers are expected to assume that all professionals are equally competent. So Family Practitioner Committees, for example, will list all contracted health service professionals in their area, but are prevented by professional governing bodies from commenting on individual performance. The only information a consumer can ask for is whether someone has passed the required examinations. Even when a doctor is suspended from the Medical Register for professional incompetence, patients will only be told that that doctor is not available to provide care for a specific period.

If informed choice is to be meaningful, patients should have access to information about the competence of the person delivering care. They should be able to find out about a professional's training and special interests, when their professional conduct was last reviewed and the results of the review.

Clinical outcomes

Kidney transplant units and *in vitro* fertilization units are the only two specialist areas where outcomes measures are currently readily available. But trying to establish the likely outcomes in other areas can be more complex and difficult. In choosing a particular hospital, for example, the patient may wish to consider not only the success rate of a particular operation but things like the infection rate or the incidence of pressure sores amongst in-patients.

However, even with kidney transplants or fertilization programmes, where the outcomes may seem relatively easy to measure, high or low success rates may be due to a number of factors in addition to the clinical competence of the staff. An IVF unit may have a good success rate because it only accepts women of proven fertility, rather than taking all comers. A kidney transplant unit may have a high success rate if it only transplants kidneys considered to be a 'good match'.

In other areas of the health service, a hospital may have a high mortality rate simply because it continues to care for terminally ill patients. The investigation of an orthopaedic unit with the highest mortality rate in one Region revealed that, unlike other units in that Region, they had no geriatric ward to which elderly patients could be transferred. After adjusting the figures to take account of this fact, it was found that its mortality rate did not differ significantly from the other units. Investigations of discrepancies such as these are important and the findings should be made available to those users who wish to know.

Access to general medical information

Within a district, there are usually at least two libraries — and often more — in the medical school, the postgraduate centre, the nursing school, the midwifery school, and the health education department; in addition there is often a patient library which supplies public-library type material for in-patients. These libraries may have little or no contact with each other, and the 'professional' libraries do not welcome use by the lay public. In one teaching hospital, for example, the librarians who run the patients' library and are paid for by the 'patient comfort fund' are not allowed access to the medical school libraries.

It is encouraging that health information offices have recently been established in some districts. In Nottingham, for example, the health promotion department has set up a service of this kind in a health centre, and in Milton Keynes the local library service, the health authority and the CHC have combined to open a town centre health information shop. On a Regional basis, Wessex has a comprehensive information system on self-help groups.

The information gap — a summary

It is evident that the information currently available to anyone choosing a general practitioner is inadequate. Information on hospital services is even more sketchy. In-patient handbooks or guides to services provided by the NHS are too often produced with the aim of creating compliant rather than informed patients. Information is usually too general to be of use to individual patients and is often out of date shortly after costly publication. Little of what is offered allows patients to make choices or to question the services provided, and there is little consensus in the NHS about what further information should be made available.

Non-NHS groups are trying to produce information that will be of greater value to users but resistance is encountered from professionals who want to control the content of publications. Increased access is also being sought to sources of specialist medical information, and greater collaboration urged between medical and public libraries.

THE WAY FORWARD

The provision of better information for consumers will require political commitment and the development of a range of technical solutions to improve current information systems. Technical solutions are needed to bring together the information currently scattered throughout various information systems. This includes information on health service policies, on the quality of services and on the outcomes of different treatment options. To bring these together and ensure they are accessible to consumers will require additional resources. These will only be made available when there is a real political commitment to users sharing information with professionals.

The evidence so far suggests that this commitment is only slowly gathering strength, and in some areas is still very much a pipe dream. For example, despite some intensive lobbying, users have failed to secure legislation to enable patients to see their own medical records unless they are on computer: a limited success story in one key area of potential patient empowerment.

We should be developing ways of sharing information and creating partnerships between doctors and patients. If doctors share information with patients, patients can then make decisions as recent research has shown.[9] The patient should decide for it is the patient who has to live with the outcome of any decision. If the production of information was also shared between patients and professionals, the end product is much more likely to be useful in helping people to make choices on their own terms.

Information Technology

If commitment to sharing information is developed throughout the NHS, there is enormous potential in some of the technical advances in information systems for helping patients to make decisions about their own health care.

With the development of appropriate technology, computer templates could be developed to list available services, using information supplied by the Family Practitioner Committee and the District Health Authorities. FPCs, for example, know the sex, age and qualifications of their contractees, together with the specialist services they are providing. Political decisions would need to be made to include further information such as standards of premises, whether they are accessible for people with disabilities, any use of deputising services, give patients access to their records. *Every DHA should also have a list of the services it provides with a name and contact number for further information.*

This information could be made available on computer terminals in places like public libraries, health service buildings, GPs' premises, in Citizens Advice Bureaux and CHCs as well as in other community-based organisations. Relatively few hard copies would be needed, and the software could be updated at points in the delivery chain, making the whole operation cost effective. Service users could obtain print-outs or photocopies of relevant sections from key agencies.

Computer technology could also be used to compile evaluative data and to make it easily accessible to the public as it becomes available. CHCs or disease specific self-help groups could feed in local information to national surveys and resource banks through integrated information networks. After initial outlay computer technology allows information to be cheaply produced, to be made widely available, and to be easily updated.

The role for user organisations

Evaluative information needs to be produced independently and not by those with a stake in the health services. Ideally this information should be produced by user representatives with the co-operation of professionals. To do so they need to be properly funded, and given the right both to obtain the necessary information and to decide on the final content of what is published. CHCs as currently constituted have neither the resources nor the intelligence gathering capacity to perform this role. There need to be new local agencies backed up by a national organisation to monitor services and to disseminate findings to community groups and to individual users.

The benefits of information being produced by user representatives are twofold. Published material is more likely to provide users with the information they want and not what professionals or health service managers believe they should know. Secondly, the process itself should involve user representatives and professionals working together in order to bring about a greater understanding of users' information needs. Open evaluation of health services can also lead to policy changes and practical improvements.

The potential of an 'outside' agency to produce information that not only improved user experiences at the point of contact with the service, but also helped to tackle existing shortcomings within the service is illustrated in the following case study.

The Community Health Council decided to produce a leaflet for the users of one of the health authority's specialist departments. Because of the degree of specialism, people were referred from all over the country. However, some people had to wait up to eighteen months for an appointment and when they did attend often waited many hours in the clinic — where sessions could last until 7 p.m or later.

Perhaps because of these long waits, many people simply didn't turn up for their appointments. But staff, who prided themselves on their clinical skills, felt helpless to alter the general conditions.

However, the CHC felt that although production of written information for the patients could not reduce the waiting time or the conditions in the clinic, if they had honest information about the way the clinic was run and how appointments were allocated, the situation would be more tolerable.

The sort of things which patients did not know, for example, were how patients were allocated. All referral letters were seen by the senior consultant who allocated the patients to the relevant consultant and the appointment time was fixed after the department had assessed the degree to which the patient was likely to benefit from treatment. So if, for example, they thought that despite their best efforts the patient's condition would not change greatly, they were given a non-urgent appointment, but if they thought treatment would be life-saving or life-enhancing for someone they would be offered an earlier appointment.

The CHC's information officer sat in the clinic for several weeks to talk to patients and to observe what happened. The doctors invariably arrived late for the clinic, so that by the time the session started there were already large numbers of people waiting to be seen, some of them having arrived early after long journeys to reach the hospital. Despite the large queues though, people were afraid to go off and have a cup of tea in case they lost their place in the queue. In other words, patients had no idea what to expect.

Following the CHC's visits, a leaflet was written describing the situation as it was, and after discussions with the senior consultant, it was clear that, despite the difficulties, some changes could be made in the way the clinic was run. For example, rather than saying in the leaflet that the doctors were late because they were 'unavoidably detained', the doctors were instructed to arrive at the clinic on time.

Finally a leaflet was produced which was to be given to each patient. It included an introduction from the consultant, a description of the clinic and how it was organised, the names of the permanent staff, an explanation of the policy of arranging tests in advance of an appointment for those who had had to wait for an appointment time, and a map of the clinic, the laboratories and the hospital.

It was then agreed that some general leaflets dealing with the condition being treated in the clinic should also be made available within the clinic.

Compared to other possible initiatives, there were several advantages to this approach. A survey of clinic waiting times would have simply highlighted a problem which everyone already knew about. A junior manager assigned to write a patients' leaflet would not have been able to use the 'rough guide' approach which gave a realistic picture of how things were. From the patients' perspective, what they got was information validated by professionals and consumers.

A new commitment

Providing more information to users may seem a simple response to a greater sense of consumerism in the health service. It is not as straightforward as it first seems. The traditional status of service providers is challenged by the call for more information: greater information sharing will lead to greater power sharing. Many professional groups remain reluctant to share the information they have: some still believe that doctors alone should make decisions about patients; other are afraid of any exposure that will reveal their own levels of competence and performance.

In this chapter we have seen the importance of the amount and the type of information available to users. If the genuine purpose of providing information is to enable users to make real choices within the health service, it must include evaluative as well as informative data. It must include details not just of service options and availability but of the comparative quality and potential outcomes of such services. It should reflect user experience as well as professional views.

Much of this information simply does not exist at present; not even in a form useful to managers and clinicians, let alone users. There are however increasing attempts to remedy the information gap, such as by establishing procedures for medical audit. Compiling appropriate information is the first challenge: providing easy access to it when needed is the next. Technical solutions and the recognition and adequate resourcing of user organisations will go some way to meet these challenges. But professional resistance and organisational blocks still need to be overcome. What is needed is a new commitment to making information available to health service users. Without such commitment there will be little change in the status quo.

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Chapter 2

EMPOWERING OLDER USERS : some starting points

KATHY MEADE AND TONY CARTER

"We've talked about our needs and who defines them. We've talked about how we're treated and how we want to be treated."

"Some of us have disabilities, some of us have a long-term illness, others are for the most part in good health. Many of us have good relationships with our GPs; others of us have not, and we all of us perhaps know of someone who seems worse off than us."

"Whatever our contrasts and differences we want to see things changed and improved."

Report of Hackney Pensioners Tribunal on Community Care to the Second Hackney Senior Citizens' Health Festival, 2 November 1985.

The concept of empowerment is complex and eludes a single definition. It includes extending one's ability to take effective action on one's own behalf, but does not end there. Strategies might range from the provision of information about a particular service, through to democratic control of decision-making bodies. In terms of older health service users, for example, empowerment could include: finding out about where you can get regular foot care; being elected on to the local planning team for services to older people; gaining the confidence to ask the doctor about your medication; speaking on health issues at public meetings.

In this chapter, we focus on three developments in the field of health promotion which could provide a springboard and a framework for empowering older users: health courses, health shops and health days. Between them they offer older people different ways of gaining access to information, structures for mutual support and confidence-building, together with the potential for initiating constructive dialogues with a whole range of providers in the NHS, local authorities and the voluntary sector. We give some examples, and discuss the problems and possibilities of these different approaches. They are not the only models within the range of what can be attempted. We know only too well that it is tempting to think about the ideal — and to be discouraged because of the difficulties of achieving that. Our advice is — do what you can and don't let the better drive out the good!

AN OLDER POPULATION

One person in five in Britain is over retirement age, compared with one in twenty at the beginning of this century. That represents some 10 million people, a number which will continue to increase well into the twenty-first century. Public health initiatives, together with the development of the NHS have ensured that many more people now survive well into old age. Not only are more people living beyond the age of 75, but they are remaining active and living in their own homes. Nevertheless older people (and particularly those over 80) are now, and will remain, the major users of both hospital and community-based health services.

THE NEED FOR EMPOWERMENT

All too often in our dealing with older people, their right to retain some control over their own lives is overlooked. Individuals and organisations working with older people frequently find it easier to do things for them, rather than enabling them to be more independent or make choices for themselves. The opportunities for older people to shape their own lives and, in turn, to shape the services which they use, tend to be severely limited.

The limitations placed on older people are due, in part at least, to the attitudes of the rest of society towards them. Statisticians, policy-makers and the media all convey ambivalent or downright negative attitudes towards older people. Ageism is endemic. The commonplace label 'the elderly' denies the diverse interests and life experience of older people, ignoring too the influences of gender, race and class. Stereotypical views see the chronological age of retirement as the start of an inevitable if not immediate decline. Inactivity and illness are seen as the dominant characteristics of old age. Our expectations of older people tend to be unrealistically low — even amongst professionals working with them. For instance, a recent Scottish study [1] found that social workers felt that, compared with children, elderly people had had their lives and, having no further contribution to make, were a poor investment. The mass of anecdotal evidence relating to older people's relationships with GPs suggests that similar attitudes may abound in medicine.

Ageism is widespread in local and national health policies and practices. There are numerous examples. For instance, policy documents continually refer to the 'burden' of the growing numbers of elderly people. Many transplant and dialysis programmes have an upper age limit of 65 years (or less). Although most deaths from cervical cancer occur in women over retirement age, routine smear testing is stopped earlier than this. The guidelines for Community Health Council membership state that they should not appoint people over the age of 70 unless there is a special reason for doing so.

In the face of these widespread and negative attitudes towards older people and their health care, it is not surprising that many older people have internalised these attitudes and beliefs and react accordingly. Confronted by comments such as "What do you expect at your age?" or "You couldn't/ shouldn't be doing that at your age", older people have learned to have low expectations of their health and well-being.

In contrast though, research confirms the continuing physical and mental competence of older women and men and the potential for lifelong development. It is also becoming clear that the ageing process itself is seldom the major cause of health problems in later life and that the effects of disease, unfitness and social factors are frequently much more significant [2]. Many problems of old age can be largely minimised, if not wholly prevented.

Access to information is one key to redressing the impact of ageism. There is, without doubt, an increasing amount of information about what can contribute to good physical and mental health later in life, what people can do to improve their own health and what services and facilities are available. Yet as one recent study said: "Very often elderly people have either not heard about it, understood it, accepted it or acted upon it" [3]. It seems difficult to get relevant information from professionals who may not always make the connection between their own specific field and more general health education. Too often, in health centres and surgeries, information material is not attractively displayed, or it is not published in ways which are 'user friendly'; for example, the text may be printed too small, there is too much medical jargon — or conversely, the information is simplistic.

Offering up-to-date, practical, non-patronising information has therefore often been the starting-point for health promotion initiatives. Health education sessions or courses, health shows or fairs, and now health shops, all recognise that face-to-face contact can be a most effective way to communicate and motivate, supplementing the limitations of written material. A recent study [4] of the information needs of elderly people confirms the validity of this approach. But simply supplying information is not always sufficient to empower older people. So, with this broad goal in mind, the initiatives described below have built on an information-giving base in very different ways.

HEALTH COURSES

Health education sessions for older people are not new; probably every pensioners' club has at one time or another been visited by a health visitor, a dietician, an occupational therapist — not to mention the fire brigade! A common pattern prevailed. The 'expert' was usually invited by the organiser to give a one-off talk on their particular subject; the pensioners would rarely have been consulted about what aspects of that subject they wanted to know more about. The most useful communication appeared to happen outside the formal session as people queued for a quiet word over tea. Since the early 1980s this traditional pattern has been undergoing considerable change. In many parts of the country, older people, in partnership with community workers and health professionals, have begun to plan their own health education. Many of these 'courses' have similar goals: to consider the myths surrounding health in old age; to look at particular health concerns and demystify medical terms and conditions; to find out about existing services and influence provision; and to explore what positive preventive action they might take themselves. Informal and relaxed settings, removed from the pressures of the patient/client role, provide opportunities for the invited expert to acknowledge the competence and experiences of older people and engage in equal and productive dialogue.

A review of health courses in the London Borough of Barnet [5] indicated that participants became more aware of their ability to enhance their own health. For instance, a majority of the pensioners indicated that they had gained a greater understanding of how the body worked and felt more able to do something positive to maintain and improve their own health. Significant numbers had joined a keep-fit class, done more exercise at home, sought advice about blood pressure or other health matters and had passed on information to family and friends. Moreover, if "a good laugh is worth a fair few pills", the benefit of a health course in bringing people together to share and enjoy each other's company was not in doubt [6]. On an equally positive note, over a third of the pensioners surveyed felt that their confidence in dealing with NHS professionals had increased.

This review of health courses also found [7] that where pensioners were involved in planning their courses, they tended to go on and establish ongoing self-help health activities after the course itself had ended. There is less evidence that health courses opened up routes through which consumers acting collectively might influence health services. Visiting professionals often acted as advocates for individuals who brought their worries to them during the sessions, but collective concerns were seldom taken any further. The pensioners themselves, by and large, did not perceive any clear channels through which they might pursue their shared goals, despite CHC representatives contributing to most courses. There are, of course, positive exceptions.

Health courses in Brent, for example, were set up jointly by Brent Pensioners Action Group, Brent Pensioners Link and the Community Health Council. This link with the CHC enabled the issues arising during the sessions to find their way on to the CHC's agenda. Because few pensioners were actually elected members of the CHC, the CHC supplemented its representation from the pensioner community by setting up a special Pensioners Health Group. Their first concern was the level of foot care services. The pensioners devised a questionnaire and distributed it through pensioners' clubs. The results confirmed that many people had difficulties in looking after their own feet and in getting chiropody services. Meetings were held with the District Chiropodist, a report was submitted to the Health

Authority and the local press provided coverage. After a lengthy campaign, some improvements were forthcoming: the service was more widely publicised and there was a small increase in staff time.

In Hackney, Pensioners Link and other local pensioners' groups developed a health course model which drew on local adult education initiatives and the experience of courses in Barnet and elsewhere. They focused their aims much more explicitly on equipping older people with knowledge, confidence and skills necessary to campaign for change. "To press service providers to look critically at the sensitivity, scope and accessibility of the services they are providing" [8] — this was the expressed goal of what became known as Hackney Pensioners Tribunal on Community Care. In an initial eight-week health course, funded by the local Adult Education Institute, sixteen pensioner participants explored the meaning of terms such as 'need', 'disability', and 'dependency', drawing extensively on their own experience as well as examining the concept of 'community care' and who provided what. They found out where information about existing service provision was recorded, they looked closely at official documents, interviewed service providers and visited local facilities. Their findings were brought to the Hackney Pensioners Health Festival and endorsed by many local groups before being presented to the Health Authority. Since then, the Health Authority has consulted with pensioners during the planning stages of new NHS provision but few of their original demands have actually been met. "Recent articles in Hackney Pensioners Press have reported a change in the pensioners' reactions to their involvement in the community Steering Group. While recognising the value of debate and discussion, they are beginning to feel that pensioners' views have very little impact on the decision makers." [9]

HEALTH SHOPS

At the few 'senior health shops' in Britain, much of the information, support and advice available at a health course can be tapped on a regular basis or as and when it is required. This has the considerable advantage of providing longer-term opportunities for older people to discuss, reflect, and find the confidence to take action on issues which require more than the stimulus provided by a short series of health sessions. The Brent Pensioners Health Resource Centre, for instance, is able to offer health-related activities on site to back up the wealth of health-related literature they provide. Supported by a part-time project worker, the weekly programme includes drop-in sessions, a wholefood shop, lip-reading, screening, relaxation and keep-fit classes.

The Beth Johnson Foundation Senior Health Shop in Stoke-on-Trent is too small for many such activities to take place on site, but as visitors explore the well-stocked shelves for information, try out computer quizzes, or sample a wholefood snack in the 'healthy eating' cafeteria, trained older volunteers (known as Peer Health Counsellors) offer them the opportunity to discuss their health interests and needs. If they wish, they can work out their own plan of action, with the benefit of continuing support from these volunteer counsellors as they carry it out. From the monitoring of this project through quarterly census weeks where every second visitor is interviewed, the change in older people's awareness and confidence to take action is apparent. When first-time visitors talk about their health, their responses are usually couched in terms of intention: "I need to think about my diet ..."; "I should talk to my doctor ...". Regular customers' responses indicate that they have begun to crystallise their original vague thoughts into action (eg. changing their diet, taking up yoga, questioning their doctor about their medication) [10]. The shops, therefore, provide a gateway not only to individual action but also to a whole range of activities such as the Look After Yourself courses, swimming, rambling, and lunch clubs that the Beth Johnson foundation has initiated at their Senior Centre and through their pensioner-run Leisure Association.

In Stoke too, a new role for older people is being carved out, empowering them to promote health amongst their contemporaries. The role of Peer Health counsellor recognises that, in various ways, we can all be health educators, in the broadest sense of that term. It is not intended to train volunteers to become pseudo health professionals, but rather to ensure that they have an "opportunity to learn some of the hard information that professionals hold close to their chests" [11], and in order to do in a more structured way what many of them would have been doing informally as part of their day-to-day relationships with their peer group.

The aims of the training are to assist participants to understand a counselling approach to working with people, ie. to listen to them and to encourage them to talk, to build up their self-confidence in sharing with others what they had learned, to develop communications skills and a greater understanding of self-health care skills [12]. The volunteers participate in a continuing training programme, including a three-day residential course, and regular monthly meetings. Sessions are included on the biological, emotional and sociological aspects of ageing. They are encouraged to examine their own attitudes to ageing and health. This greater insight is helpful when communications skills are explored, and time is spent analysing the ingredients of helping relationships. Practical information about the services available locally is also covered. Case study techniques, role play, and small group work complement more formal presentations by the project workers. As a result the boundaries to lay people's knowledge and skills and the nature of the support they can offer to each other are being extended.

On the first training programme there were eleven 'trainees' — eight women and three men, aged between 52 and 70. "They were in no sense superhuman beings — just ordinary people from ordinary jobs, all with their own health difficulties (arthritis, rheumatism, insomnia, indigestion and so on)." [13]

As well as staffing the health shop, some Peer Health Counsellors regularly visit local residential homes where they lead gentle exercises and discussions. Others work on Care Line, a service where approximately forty frail, housebound people are telephoned daily and kept in contact with the outside world. Future developments include a pilot scheme in a doctor's surgery where they will offer support and advice on active and healthy retirement to older patients.

In facilitating the process by which older people can obtain information and feel confident to define new health-related goals for themselves, the Peer Health Counsellors are actively empowering both themselves and their peers. The impact on self-health is significant. What is less clear, though, is how such a network of older people can link up with the formal health services and other providers to contribute to environmental and service developments of benefit to older people as a group.

HEALTH SHOWS

Pensioner health days, Age Well shows, health fairs or festivals have proved to be yet another successful and popular way of offering older people the opportunity to gather the information they want, in a variety of ways but all within the space of one or two days. In addition to picking up leaflets, and asking questions at the many stalls and stands covering different health matters, pensioners can join in a programme of workshops. Typically, pensioners groups/clubs have stalls and put on demonstrations of their activities. In 1985, as part of the newly launched Health Education Council/Age Concern Age Well campaign, eight major cities put on health shows attended by some 20,000 older people and professionals.

Such shows, and others in smaller localities, by their ability to attract significant numbers and bring together a broad spectrum of activity, enthuse and inspire. They generate new contacts and new ideas and create a sense of being part of a whole network of older people and agencies interested in improving health in old age. Stereotypes of older people as passive recipients are challenged as perhaps are images of remote and unfriendly professionals. As the account of Age Well shows says, "Each show introduced hundreds of older people to ideas of self-help, self-confidence, and participation with others — ideas which should lead to action and to the articulation of new and relevant demands upon existing services [14]. In many locations, health shows are the first events ever co-ordinated by statutory, voluntary and local pensioners' organisations. With one collaborative event successfully staged, the possibility of other inter-agency events involving older people themselves is opened up.

In Huddersfield, for instance, links were established which reinforced existing local authority concern about poverty, and led eventually to a Poverty in Old Age group, bringing together several local organisations - statutory (health and local authority), voluntary and pensioner. One outcome was a major two-day conference on "Health, Wealth and Poverty". Others included two local health forums and a seminar on health issues concerning older women from ethnic minority groups. The right of older people to be represented in the planning of any health promotion activity in Huddersfield has become firmly established.

Two important issues emerge from these examples of older people, both individually and in groups, beginning to carve a role for themselves in the planning of services and facilities. Firstly, that the interpretation of notions like partnership, community participation and self-help needs to be broadened. As the Ottawa Charter for health promotion [15] suggests, empowerment is connected with "concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health". This has political connotations at a time when considerable emphasis is placed on individual choice and personal responsibility of health. In Huddersfield, Hackney and Brent, the development of personal self-health care has gone hand in hand with community action to influence public health policies, services and structures.

Secondly, consideration needs to be given to developing democratic organisational structures through which older people can elect people who represent their interests. Mention has already been made of CHCs. There are, of course, several voluntary organisations such as Age Concern and Pensioners Link working with and for older people. These are often effective at lobbying but it is questionable how far they can or should represent older people. Here the burgeoning pensioners' movement should help, but so far it has paid comparatively little attention to health issues.

CONCLUSION

In combination, these three types of initiatives — health shows, self-help health courses, and health shops — highlight different routes to empowering older people, particularly in respect of their own health care. From a shared goal of opening up access to information among older people, these approaches have moved along quite unique, challenging and thought-provoking paths. Unfortunately, like so many initiatives with older people, the potential will only be realised if they can be transformed from imaginative one-off events, (often initiated in the voluntary sector), or isolated, geographically confined projects, into mainstream activity. What also needs urgent consideration is how the collective concerns and interest, perhaps informally aired by older people, say on a health course, can find recognisable channels of expression.

Those involved in the processes of empowering older people, through facilitating their access to knowledge and skills, through assisting them to gain representation on decision-making structures are only too aware of the resistance of social structures to change. This could not be more acute in a political climate which is not committed to a more equitable sharing of power and resources. Empowerment is an ambitious enterprise, but it is firmly on the agenda.

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Chapter 3

CONSULTATION FORUMS WITH CARERS:
MARTIN BOULD

INTRODUCTION

This chapter looks at the purpose and practical implications of setting up consultation exercises with carers. The word 'carer' is used in many ways: it is taken here to mean family and friends looking after someone who cannot manage alone at home due to illness, old age or disability. Drawing largely on the experience of the consultation forums run by the King's Fund Carers Unit, but also on alternative approaches adopted in Birmingham and Newcastle by other agencies, the chapter highlights some of the limitations and practical difficulties of consulting carers, as well as the positive outcomes that can be achieved.

WHY CONSULT CARERS?

Consultation has become an accepted part of democratic decision making processes. It can be justified in a variety of ways. For example, it contributes to management efficiency by providing information and understanding that will lead to better 'products'. Consumers have a wealth of knowledge and experience which can contribute substantially to the design of new products and services. Few commercial products are launched without a trial run. Advertisers everywhere field-test, and manufacturers use 'focus groups' to bring together consumers to discuss their preferred product qualities. The lessons are well understood in the commercial world. Consulting with carers uses the same broad approach. Their knowledge of the individual needs of the person they look after, and their experience of receiving or trying to get services, mean they are a source of informed comment and constructive thinking. By bringing together carers, information is gathered that would not otherwise be to hand.

Consultation also has a value in terms of public accountability when it reflects a genuine wish for openness and is not simply a token process designed to appease public opinion. It can demonstrate that other people's views and wishes are being taken into account and that policies, or in some cases information materials, are not just the products of a random set of values. It allows consumers' experiences and values to be substituted for those of professionals and officials, whose views so easily and so habitually dominate policy formulation and implementation.

Why consult carers? They are rarely the direct recipients of services (which generally go to the people they care for). No one *has* to take their views into account. They are a diverse group, spanning all ages and disabilities, both as carers themselves and in terms of the people they care for. They are not organised or resourced as a group to participate in decision-making or policy planning processes. Individual carers indeed do not necessarily feel any common identity — some even resist the term 'carer'.

This diversity means that consulting carers is not straightforward. It also means that consultation is all the more important. Effective consultation with carers can provide an authentic account of the issues that they feel matter most — information which would not otherwise reach policy makers. Participation in consultation exercises can lead carers to join in other activities. Joint activity will ultimately allow carers to play a more proactive role in policy making through continuing dialogue and representation.

This chapter will try to demonstrate how consultation is strengthened if sufficient consideration is given to the practical management needed to ensure the active participation of carers.

The consultation exercises described below have provided a basic level of involvement for carers through forums in which their voices could be heard. Where carers were isolated, under-valued, and disenfranchised, they could speak out on their own behalf about their own needs. In terms of recognition and improved attitudes of service providers, they have had a powerful impact. From the carers' point of view, they have had their needs placed onto a local or national agenda and as individuals they have contributed their own experiences to a process which will help improve matters for others in a similar situation. In that respect, the forums described here have remained true to the principles of honesty and respect which are prerequisites for true consultation and empowerment.

THREE PROGRAMMES OF CONSULTATION WITH CARERS

1. The King's Fund Carers Unit

Background

The King's Fund Carers Unit was set up in 1985 to produce information, education and training materials for carers and for professionals working with carers. The Unit aimed to improve the range and quality of information available to carers themselves, and to commission training packs for professionals. It therefore produced a programme of material including a handbook for carers, '*Caring at Home*', and a video-assisted training pack '*Carers*'.

Funds were obtained from the DHSS (now DoH) and the Health Education Council (now HEA). The broad remit of information, education and training was agreed in the terms of the Unit's grants, which were to last three years. But a large measure of discretion over what to produce and how to go about it remained with the King's Fund.

From the beginning, the Unit decided that a programme of consultation with carers would be set up. Why was this decision taken? The first reason was to obtain information about what carers needed. By asking carers directly, the

King's Fund could learn about the difficulties they experienced in getting help and support, and discover what information would be useful to them. Health education messages have been criticised for reflecting the views of professionals and experts, instead of telling consumers what they really want to know. The King's Fund was determined to avoid this trap by consultation, discussion and field-testing materials.

The method we used was setting up local meetings for carers in Middlesborough, Leicester and Worcestershire (meeting in Worcester and Evesham). These areas were randomly chosen, but because they were geographically separate and had different characteristics they provided a national dimension. Meetings took place quarterly for two years (1986-8), so we had the opportunity of talking with the same people over a period of time.

We chose not to use existing carers' groups, although on the surface this would have been simple and straightforward. There are many carers' groups in existence today, and whilst an existing base in local organisations is always helpful, we would still make the same decision not to rely on a single existing group. We believe that consultation needs to be an activity with a single purpose, clearly owned by the agency which initiates it, and open to public scrutiny. An existing group will have its own agenda, membership, and dominant individuals, whereas a new forum means that all those with an interest in the discussion, including unaffiliated members of the public, can take a full and equal part.

Meetings were open to all carers, regardless of the age and disability of the people they care for. Many workers (and carers) express concerns that carers who care for people with one disability will have nothing in common with those who care for people with a different disability. In fact, individuals responded positively to sharing experiences with others, and we take the view that there are many common needs (see our leaflet *Carers Needs — a 10 Point Plan for Carers*).

In general, carers who attended our meetings were not well known to each other and represented a reasonable (but never a perfect) spread of ages and disabilities amongst people cared for. Carers with access to cars are much more likely to come (even from several miles away) because of the speed and convenience of private transport. People who could conveniently make arrangements for the person they looked after were well represented — for example, where a school or centre was open, or if a person could safely be left alone or with another member of the family. But there was not much evidence of people making elaborate, expensive or unusual arrangements for substitute care. Going out was still a relatively rare experience for many of the carers who attended.

For our initial meetings, we kept to an open agenda with small group discussion. We tried to present clear themes for each meeting, wherever possible structuring group tasks in order to emphasise positive experience or suggestions for practical action. This helped counterbalance the genuine difficulties and hardships which many carers faced.

Examples of themes included: good and bad experiences of various subjects; (e.g getting help from a GP); getting a break; hopes and worries for the future; help at home; and how to get the information you need.

Outcomes

Over the two year period when these forums met regularly, we built on the relationship we established in the early discussions. Carers were able to contribute in a major way to our programme of information material through discussions of drafts of booklets, a list of carers' rights, videos about carers, self-help groups, and new policy initiatives for carers. As a result of the emphasis they gave to respite care, we altered our plans and produced a guide for carers on the help available and how to use it. The process was much closer to field-testing of materials and required prior consideration of written materials (both short and long), sometimes backed up by questionnaires. We also set up special additional meetings with carers, writers, and trainers responsible for particular projects. All these proved very successful ways of harnessing input from carers. But it is doubtful whether they would have been possible without the initial investment in open agenda meetings which established common ground and mutual confidence.

Meetings tended to get smaller over the two years, with a nucleus of about 15 people. However, we were able to get a lot of help from these carers because the format of the meetings (still using small group discussion) worked well, and because we knew each other. When numbers came down to single figures, we had either to revitalise them with more publicity, or else agree it was time to withdraw.

We remained aware however that carers were more concerned with services than with the production and distribution of information. This had been a definite and uncomfortable outcome of the initial consultation. Although we were not able to renegotiate our brief at that stage, we did include a major project for planners and managers of services entitled '*A New Deal for Carers*'. This involved several months of research and consultation with people working with carers, with carers themselves and with their organisations and it is intended to make a major contribution to the debate on community care. When we put forward proposals for further funding, they included a significant amount of work developing initiatives to improve services for carers.

2. Other examples of consulting carers

Birmingham Community Care Special Action Project

The next example demonstrates the value of a local authority initiating consultation about its own services. The Community Care Special Action Project was set up to help Birmingham

City Council's services become more responsive to the needs of carers and people with disabilities. Open consultation meetings with carers became an influential part of the project's work.

The consultation was built around a clear strategy and a continuing process. An initial event in the City Hall attracted publicity and demonstrated the commitment behind the project — but the carers consultation was a rolling programme which took place in every part of the city. Local meetings were organised, with sitting expenses available, and senior managers and planners present as group leaders to hear at first hand what carers had to say. Lunch was provided and translators available for those for whom English was not their first language.

The thoroughness of the overall strategy was matched by clear procedures and a well defined purpose for the meetings themselves. The two-hour timetable including buffet lunch was tight, but closely adhered to, so that there would be ample time for group discussion. Two themes were proposed to groups: help at home and getting a break. Carers were assured that the points they raised would be passed to the relevant departments for comment and action. A newsletter was produced containing a record of the meetings.

By and large, carers did not have new things to say. They wanted better information and services to reduce their isolation and to improve the quality of care and the social relationships for people they looked after. There was an unexpected emphasis on transport. But, as elsewhere, it was the insight into the way in which services did (or did not) reach carers, and the practical difficulties of day to day experience, which provided new lessons. Amongst the most beneficial results was the opportunity for senior managers to hear these points and the recognition gained by carers in making them. The positive approach adopted by the consultation team throughout the whole exercise produced dividends and city councillors heard very favourable feedback about the meetings from their constituents.

The consultation had the desired outcomes: a thorough compendium of practical improvements wanted by carers was produced for committee and sent for response to service providers in health and transport authorities as well as the City Council. A continuing programme of information-giving activities was launched by a city-wide information day and followed through by Carers Week at council neighbourhood offices, whose role is to link consumers with services. Further rounds of carers forums have taken place during the life-time of the Special Action Project, as well as a programme of talks, information days and local events for carers.

The positive response to the original meetings has meant that council officers and elected members are beginning to understand how consulting carers and building their values into services act as positive forces in planning and management across many departments. The personal involvement of senior officials in face to face contact with consumers has, with other changes, contributed to a new culture in service provision. And finally, many detailed improvements in service quality are being examined with a view to implementation at no additional cost — using the same resources in a new way.

3. Newcastle-upon-Tyne Mental Health Unit

In Newcastle, consulting carers has influenced the development of an individual day care and residential centre. Here, I draw on a report describing an initiative by the Mental Health Unit in Newcastle-upon-Tyne. The manager and staff of a centre providing day care and short-stay residential care for elderly people with mental illness wished to obtain views on changes in services in advance of a planned reorganisation. Staff views were surveyed and regular meetings with other local agencies were set up. A consultative meeting with carers of confused people was planned to complete the picture.

There were a number of differences to the models so far described. Due to pressure of work, staff themselves did not organise the meeting. An outside trainer was engaged to set up and facilitate the event. The meeting was a full day event and about half the sixty people present were workers and half carers. The carers reported some feeling that there was too much jargon, and were themselves not always very forthcoming with their comments — a phenomenon not usually observed elsewhere! The final difference was the inclusion of presentations and panel discussion by senior managers and professionals, in a style reminiscent of traditional meetings.

It is clear, however, that there were many similarities and many successes. The meeting was open and widely publicised, although not very successful in contacting more than a minimum level of carers who were not associated with organised groups. Small group discussion was used in both morning and afternoon sessions, and clear, simple tasks were set: in the morning, to list the needs and problems of elderly people with mental illness and their carers; in the afternoon, to list three necessary improvements to new or existing services.

The additional time available allowed the use of a 'market place' to finish the day. Those present could put ticks against messages for service providers on flip charts round the room. The messages were drawn up by group leaders. They included the message for GPs that receptionists keep people away from the doctor; for the hospital that people aren't told what is happening; and the simple message for social services: Where are you? Can't you work faster?

This forum, although a 'one-off', was an imaginative outreach exercise which contributed to the development of the Unit's thinking. It brought carers and professionals together and distilled the key elements in the services provided.

LESSONS LEARNT FROM CONSULTING CARERS

The above examples have illustrated the very real benefits that can be derived from consulting carers. However any form of public consultation needs to be carefully organised. Public meetings are often criticized for poor attendance (often the result of inadequate planning) and impossibly technical discussion. Many service providers will confess however to certain misgivings about facing consumer complaints — and perhaps organised lobbies — at first hand. Such misgivings are not confined to the statutory sector: many voluntary organisations have shied away from consulting their public.

Consultation is not straightforward. Every consultation is a learning exercise — for all those taking part. What follows are some of the guidelines about style and practical implementation that have emerged from the lessons learnt to date from consulting carers.

Planning the consultation

- **Timing**

Careful timing is important. It is necessary to begin consultations at a sufficiently early stage for views to really influence decision-making. Local consultation programmes often have to struggle to keep up with timetables for policies and plans that are being formulated centrally. Nevertheless, there is a stage in the development of strategy where outline plans turn into programmes of action or projects, and it is here that views can still usefully be incorporated.

- **Keep an open agenda**

Meetings should be planned to provide forums for views and values to be reflected, not to elicit a list of anticipated responses. Even when the ultimate aim of consultation is to get views on quite detailed issues, a shopping list is not necessarily helpful. Prepare open-ended questions on broad themes in order to encourage maximum discussion.

- **Know your boundaries**

At the same time it is necessary to clarify which subjects and which possibilities for action come within the remit of the consultation. Carers for example are often angry because they have been ignored or let down by service-providing agencies for several years. Whilst accepting that this has been their real experience, not every point can be dealt with, and some key issues, such as political decisions on resources, cannot be tackled by the meeting or by the changes under consideration. On the other hand, where something can be done about an issue raised, it must be followed through.

- **Keep groups small**

One of the most powerful devices for effective consultation is to use small group discussions. Large meetings are very cumbersome tools for obtaining information. Fewer people contribute and those that do tend to offer platform positions or rhetoric. In smaller groups of 6-15 people, everyone can introduce themselves and be given time to speak in discussion. The format means that every individual is taken seriously and their comments are offered as personal experience, rather than in a confrontational way. A much wider range of subjects can be covered and reported back from a small group than from a larger meeting and although more labour intensive (since several group leaders must be found and briefed), they yield a rich harvest of practical comments.

- **Take responsibility**

The organising body must provide a clear agenda and take responsibility for the meeting, preferably through the presence of a lead worker with a central stake in the consultation exercise. Those initiating the consultation must demonstrate a willingness to hear and respect the whole story participants wish to tell — not just the bits which seem immediately relevant. Be prepared for the challenge of a forum where you have no idea how many people will turn up, and where you are giving consumers the chance to say what they think.

- **Target disadvantaged groups**

Some carers may be doubly disadvantaged if plans are not made to specifically target them. Be aware that an open style of meeting may not reach out very effectively to black and ethnic minority carers, failing to bring them forward to participate and to overcome language difficulties. Outreach work with local community groups can be one way of tackling this and individual or small group interviews may be necessary.

It is also important to consider how to involve the people who are being cared for. There are few opportunities for joint discussion between carers and the people for whom they care. Yet many issues centrally affect the quality of life of both groups — respite care being a prime example. It is recognised that carers speak more freely when the person they care for is not present, but consideration should be given to additional ways of bringing representatives of both parties together to discuss community care policies and service delivery.

Publicity

- **Use local networks**

The first step in the organisation of meetings is to make contact with existing local networks of voluntary agencies. Do this for practical reasons as well as for simple courtesy. Take advantage of the diversity and flexibility of approach in the voluntary sector. Umbrella organisations like CVS (Councils for Voluntary Service) and the coordinators of projects specifically for carers (such as Crossroads) often respond with enthusiasm to the suggestion of setting up carers forums.

One of the concerns of the King's Fund Carers' Unit was that local agencies sometimes see nationally organised initiatives as interference or, at best, 'parachuting'. As far as possible, we took care to explain our reasons for contacting them and to involve groups without imposing unwanted workloads on them. It is important to remember that they have their own agendas and priorities.

In order to establish effective local alliances, try to take on as many local suggestions as possible about who to invite, where to hold meetings, the day and time, etc., while at the same time retaining a clear view about the purpose of your consultation. You may possibly have to overcome some doubts about meetings organised on a public basis and involving a wide range of agencies. It may be helpful to organise a pre-meeting to tell local workers what plans are, and to ask for their suggestions. Most of the carers who attend forums do so (according to feedback) because they are told about it by a professional worker. It is certainly worth asking those workers who support the idea of consultation to personally invite two or three carers they know.

- **Advertise widely**

Aim to reach as many participants through as many networks as possible, using both local media and existing organisations. Extensive publicity is necessary to get in touch with carers. Most organisers of carers consultations find themselves producing leaflets and posters on a large scale, and undertaking direct mailshots to every organisation likely to have carers amongst its members. Mailings through libraries, clinics and community projects (with plenty of advance notice for newsletter entries) are likely to be valuable. Inclusion in the Family Practitioner Committee mailing and distribution through home helps or community nurses are also possibilities. Where appropriate, leaflets translated into the relevant ethnic minority languages should be produced and distributed in consultation with local organisations and any workers with whom you have built up a good relationship.

A significant minority of participants will come through articles in the local newspaper or items on local radio. This kind of publicity is a vital way of reaching people who are not in contact with organisations, and it also serves to underline the public nature of the consultation and to reinforce other publicity. A first consultative meeting is certainly 'news' in terms of the local media, and a press release should be sent out. Any later meetings which focus on new issues may also attract coverage.

Managing the event

- **Facilitate attendance**

In planning meetings with carers try to make it easy for them to attend. There is no best time: morning, lunchtime, afternoon or evening. Different times suit the circumstances of parents, of carers who have day care for the person they look after, or of carers in employment. Alternating times can allow different carers to participate on each occasion in a series of events.

Paying travel expenses and for someone to sit with the person they look after can make it more possible for carers to come. The availability of expenses should be well advertised (even though only a handful of people are likely to claim them). An accessible and reasonably central location, with car parking, is another great help for carers whose time is at a premium.

It is important to offer carers some greeting and hospitality, but your catering will have to be expandable. Coffee and biscuits are easy enough. If you are offering a buffet lunch you will need adaptable people to run it! A significant point is that if small groups are held in corners of the same large room, the level of background noise can cause difficulties for people who are hard of hearing. Separate small rooms are better, if at all possible.

- **Timetabling and procedures**

At the start of the consultation, explain who you are, why the meeting has been called, and what is going to happen during the meeting and afterwards. Introduce any key people such as group leaders.

The timetable must be carefully worked out to allow sufficient time in small groups. It should allow for at least 45 minutes group discussion, plus introduction, report back, and time for refreshments. Allocating people to, and moving between groups can take several minutes. Do the allocation when people arrive, if you can.

Notify a finishing time for a meeting and keep to it. An optimum length of meeting seems to be two hours. Participants do not want shorter meetings according to feedback, but carers have difficulty in leaving the person they look after for more than two hours.

- **Recognise the need for support**

Carers often use consultative meetings as support groups. Even though the discussion is about policy, carers value the meetings because of the emotional support they get from other carers. For many, it will be the only place they can talk about what they do and what they feel. No one may ever have asked their opinion before. In small group discussion, carers will need time to tell their stories and may disclose quite harrowing circumstances. Even if this involves tears, anger or frustration, it is still an honest account of their experience. Do not discount what carers have to say in this personal way just because it does not fit with neat conventions of 'committee behaviour'. However, group leaders may need to state at the beginning of the discussion that expressing feelings such as anger or sadness is perfectly acceptable.

You may need to plan some provision for those carers who present a pressing problem concerning their own situation. Sometimes it is possible to arrange for individual points to be taken up privately after the meeting by appropriate professionals who have acted as group leaders. The contact names and meeting times of any ongoing carers' support groups should also be to hand.

- **Manage professional input**

An important practical issue is deciding how to fit paid workers into the structure of a meeting designed to discover carers' views. At an open meeting anyone can come, including people with a professional interest. In general, their presence should be welcomed: you want them to hear what carers have to say.

But it is essential to limit the freedom of professional workers to speak. In past meetings, workers have habitually expressed their own or their agency's point of view, sometimes speaking across carers and often using jargon. One technique is to give professionals the choice of attending a group discussion for professionals, or remaining silent in a carers' group. Another (used by the King's Fund carers forums) is to establish a rule that a professional (apart from the facilitator) can only speak after a carer has spoken, thus preventing dialogue which excludes carers. Some meetings where services are being discussed adopt the rule that individuals may not be criticised by name.

- **Listen and respond**

Consultation does not finish with the end of the meeting. An essential part of the relationship you establish with participants is telling them what happened at the meeting and afterwards. Minutes are greatly appreciated — feedback shows this is true even of quite full minutes.

Views may not have been expressed or information given in the form you wanted. Carers will not come up with neat solutions and will not use the bureaucratic and technical language common to most organisations' planning processes. So it is important to hear basic messages about key points (without becoming defensive), and to use lateral thinking or problem-solving skills. Organisers must pick up the many insights and messages in personal experiences and group discussion. It is not a question of ignoring the main messages of a meeting, nor of basing policy on anecdotes or individual comments. The task involves checking back, generalising, and spotting themes which recur over several meetings or which have an exact fit with subjects central to the consultation. These interpretative findings must be channelled back into the decision making process after the meetings. Communicate how this has been done.

There may be difficulties in responding to a consultation process when you are told that what you are proposing or providing is completely wrong. This may be said with anger; or the point made politely; or it may be silence that is conclusive. How then can you see consultation as a process which helps puts others' views and values at the centre of your endeavours — when you are committed to doing something they think is unimportant? For example, in the King's Fund case, it was obvious that carers appreciated the need for better information, but they were mainly concerned about the poor availability and uneven quality of services.

You can still benefit from consultation in these circumstances, unless what you are proposing is actively opposed. You have gained an increased understanding of needs; you may be able to make significant alterations to your plans; you may even be able to renegotiate your brief with your funders, or with policy makers. Only if none of these apply, will your consultation have served no purpose at all.

CONCLUSION

The three programmes of consultation described earlier in this chapter illustrated the very valuable benefits that can be derived from consulting carers. Such exercises are examples of the foundations that need to be laid for a more organised and accountable voice for carers. For these to be firm foundations, strenuous efforts should be made that consultation exercises bring together a wide cross section of carers and cover the broad spectrum of issues which they themselves feel important. Effective consultation depends however on careful preparation and delivery and the thorough consideration of outcomes. The carers themselves must believe that their precious time has been well spent. The potential gains however are countless: from initial contact made through consultation a sustained process can develop which recognises, supports and empowers carers in the long term.

Chapter 4

INVOLVING PEOPLE WITH LEARNING DIFFICULTIES IN MEETINGS:

ANDREA WHITTAKER

The meeting had been in progress for twenty minutes. There was a knock on the door and in came the last member of the committee. He was empty-handed. He glanced rather uncertainly around the room. He was greeted briefly and invited to take a seat. Discussion on the current agenda item continued. After a while, the latecomer began to join in: some comments were relevant to the topic — some were not. Now and then, the latecomer would take up a point enthusiastically and talk at length in a way which appeared to the rest of the committee to bear little or no relation to the subject under discussion.

Nothing particularly unusual in that brief scenario you might say. We all know people who come to meetings late, have forgotten their meeting papers, and who waste everyone else's time by waffling on about their own particular hobby-horse! However, what made that scene different from dozens of similar occasions was that the latecomer happened to be a person with learning difficulties (former term: 'mental handicap').

It is now quite common for policy and planning documents about services for people with learning difficulties to include statements about the importance of service users participating directly in service planning and delivery. Unfortunately though, these are often no more than general statements of intent and nothing is said about how these intentions will be turned into action.

This chapter discusses one way in which service users can participate in the development of services, looking at how people with learning difficulties can play an effective part in meetings. It focuses on meetings specifically because, however much we may complain about their frequency or question their usefulness, they remain an important and often-used method of communication in service-providing agencies such as health authorities or social services departments.

This chapter focuses on people with learning difficulties, partly because of the author's experience (as Advisor to the self-advocacy organisation — People First) [1] and partly because general progress towards participation by service users in Britain is more widely developed amongst people with learning difficulties than amongst other groups such as people with physical disabilities or mental health service users. Through membership of student or trainee committees in day centres and the activities of groups such as People

First, many people with learning difficulties have become skilled at speaking up for themselves and identifying what they want from services.

To return to the scenario described at the beginning of this chapter. A keen observer of the scene might have noticed other ways in which people were behaving differently. Most contributions to the discussion would be acknowledged in some way by others present — by a nod of the head, murmurs of agreement (or disagreement), by eye contact; in these small ways, individual contributions would be woven into the general ebb and flow of the discussion. But comments from the person with learning difficulties seemed to be handled differently. Sometimes they were passed over — almost ignored. If the comment seemed irrelevant then silence descended and people seemed to be feeling rather uneasy. On the other hand, sometimes he was given the floor and allowed to talk at considerable length, unchecked by fellow committee members or by the chairperson. But when he stopped, discussion among the rest resumed as if he had not spoken at all.

This story illustrates several key issues which need to be considered when thinking about how to involve service users most appropriately in meetings.

PROFESSIONALS HAVE PROBLEMS WITH PARTICIPATION...

One of the most important points to emerge from the story is that it isn't only service users who may lack the necessary skills. Even when professionals are committed to the idea of participation, they may still find it difficult. The fact that someone may have worked with people with learning difficulties for many years may not mean they find this sort of communication easy. For some people, moving up the career ladder may mean they end up spending little or no time in face-to-face contact with service users. But even when people do work on a daily basis with users they may still never really get to know the people they work alongside.

Genuine participation in situations like the one described above means involving service users as real partners. Services do not tend to foster that sort of equality of relationship. People with learning difficulties are used to a much more passive role, to being on the receiving end of services which have been planned and shaped by other people who have decided that they know what is best for them.

As a result of all this, people may feel uncertain about how to react or even how to talk to a service user in a group. They may feel impatient if the pace of the meeting seems to be slowing down; or frustrated by the need to explain or clarify more often than usual. Whatever the reason, it is not unusual for professionals to be anxious about the idea of working with a person with learning difficulties on the basis of participation and partnership.

PEOPLE WITH LEARNING DIFFICULTIES AS PARTICIPANTS

People with learning difficulties have demonstrated time and again that they can make extremely effective contributions to all types of discussions — as conference speakers or in meetings or in small group discussions; the growth of self-advocacy has provided many more opportunities for people to express themselves. A person with learning difficulties will often say something which gives fresh insight to the discussion. Listening to someone speaking of their own direct experience can be a most effective way of keeping the real world in our minds. It can help prevent discussion drifting off into the realms of theory and help everyone present focus on people — rather than beds, buildings, service structures and systems.

Nevertheless, when it comes to being involved in meetings, it is unlikely that the service user will have the same level of skills as others in the group. Most members of the group will be used to attending meetings — usually as a regular part of their working life, but often as a part of their social and leisure activities too. They will have little difficulty in holding conversations on a one-to-one basis as well as taking part in group discussions. Most people with learning difficulties, however, have not had the opportunities to develop and practise these skills.

There are various reasons for this, most of which are the result of the way other people have acted towards them. For a start, people with learning difficulties have not been expected to have opinions or ideas of their own — or not ones which were worth discussing with other people. In many cases they will have spent most of their waking hours in an environment where other people told them what to do and where to go. Responding to these sorts of 'orders' doesn't really require any verbal response at all. Even questions can usually be answered with a brief 'yes' or 'no'. A person's latent abilities may have remained hidden because of the low expectations of those around them.

It is not surprising, therefore, that the service user who joins a committee or working group may have some catching up to do in terms of learning new skills and may need special support in order to contribute effectively to the discussions. There are several ways in which the group as a whole can offer that support.

COMMITMENT

Without the commitment of a majority of people in a group involving service users, their involvement is unlikely to be more than tokenistic, failing to develop into a real partnership and sharing of power.

Real commitment is about more than a written statement of intent (although that may be a useful starting-point). It means individual group members believing that service users have a right to be involved and that they have a valued contribution to make. At the start, it is unlikely that everyone will have the same degree of commitment or hold the same views on participation. Some may be for it, some against, and others may be willing to give it a try. Sometimes user participation may have been 'imposed' on the group by more senior colleagues, causing possible resentment.

So, before service users become involved, the group needs to talk through how they feel about the idea, being as frank and honest as they can. A brief discussion at one meeting may be all that's needed — but it may take longer than that. Take your time — but take care that discussion doesn't become an excuse for inaction!

The best way of breaking down barriers and prejudices is to get to know people as individuals. Think about where the potential service-user members of your committee or working group are likely to come from; it might be a local self-advocacy group or a student/trainee committee at a day centre. Invite a few people from that group to meet your group; this gives both sides the chance to explore whether they want to work together.

One way to arrange a meeting would be to write to the group, asking if they would be willing to meet members of your group. The letter should state clearly and simply why you would like a meeting, including perhaps one or two very practical examples of issues you would like to work on with service users. This meeting might form part of the agenda of one of your meetings, or the service users might like some of your group to attend one of their meetings.

When the IDC (Independent Development Council) [2] decided it wanted to involve people with learning difficulties as members of the Council, it invited representatives of People First to attend one of its meetings as observers. These observers then reported back to their colleagues in People First and the group was then able to decide whether they actually wanted to become more involved with the IDC.

Whatever you decide to do — keep it simple! Avoid lengthy letters and complicated enclosures. Avoid large gatherings of people. This is all about getting to know people as individuals — as potential working partners. As in other situations, a few people meeting together over a meal may do more to increase understanding and commitment to collaboration than any amount of formal education or training.

THE IMPORTANCE OF LANGUAGE

A chairperson was summing up at the end of a day's workshop. The day had begun with a contribution from two people with learning difficulties who had advocated passionately for the abolition of the term 'mental handicap'. This had obviously affected the majority of participants who made considerable efforts throughout the day to remember not to use that term. The chairperson commented on this, ending with "We have learnt that we must watch our language — at least in the presence of people with handicaps".

A joke? Or a sad reflection of how shallow our commitment and understanding can be? The way we speak about people with disabilities says a great deal about how we value — or devalue — people and how serious we are about working with them as partners in planning and developing services. "A lifetime of being labelled has made labels a major issue" [3] and learning to use descriptive terms which are acceptable to people with learning difficulties is an important issue.

But it is also important to think more generally about the language we use — particularly in meetings. We need to talk clearly and simply and avoid jargon. If a service user does not seem to be following the discussion in a meeting it is all too easy to assume that that's part of being handicapped. It may be that the discussion is not particularly meaningful or clear for others too. The onus is on everyone present to make the discussion comprehensible. This can be challenging at times but is likely to result in greater clarity and understanding not only for the person with learning difficulties but for all those present.

LISTENING

Listening is something we tend to do automatically, without thinking consciously about it, particularly when we are with people of similar interests and background who "speak our language"; it rarely occurs to us that we might need to develop our listening skills; but if we did, some of us might become better listeners!

When we join a group such as a committee or working party, however, it can take time for the group to become comfortable in communicating with one another. So really listening to someone who is a newcomer to the group, and whose opportunities to develop conversational skills, think logically and get a message across clearly may have been severely limited, requires a deliberate effort on our part and even the development of new skills.

For example, the person with learning difficulties may say something which seems to be way off the point. But a good listener will often be able to detect a link. It might be the last word said by another person present. The person with learning difficulties has picked this up and related it to his own experience in some way. Other members of the group need to discover what this link might be — building on it to draw out something meaningful to the rest of the discussion — perhaps also helping to lead the service user 'back on to the track' and fostering his involvement in the group.

The baseline must always be "Have we explained this carefully enough?" or "Have we provided all the support that this person needs in order to participate in the discussions?" It should never be "Oh, he can't be expected to understand that idea or that document".

This type of listening needs time, patience and practice! But it is crucial if we are to enable service users to be effective participants.

REMEMBER THE USUAL PITFALLS OF MEETINGS!

It is useful to remember what happens ordinarily at meetings; there are people who talk too much while others may say virtually nothing; some people stick to the topic while others are inclined to wander off it! If the group is really committed to participation, they will want to do all they can to ensure that the service user feels involved with what is going on. But this does not mean making the service user into some sort of 'special' member of the group, entitled to 'special' treatment. As the story at the beginning illustrates, there is a danger that concessions may be made for the service user which are not applied to any other members of the group. On the other hand, the service-user member should not be expected to act as a 'super-participant' — never straying off the topic, never left alone, and expected to contribute to every single agenda item!

In short, although he may need extra help to become a real part of the group, the service user should be treated as far as possible like any other member of the group. There is a very important balance to be struck here — and it is not always easy — but a good chairperson should be able to ensure that this is achieved.

THE FEAR OF TOKENISM

Many people express concern about the dangers of tokenism, citing examples of people with learning difficulties being used as the token consumer. This can happen in a number of ways and for a variety of reasons. Service users may have words put into their mouths, or be asked questions in a way which allows only the answer the questioner wants to hear ("Don't you think we ought to....." or "Wouldn't it be a good idea if......"). They may be "paraded" in front of an audience like some sort of special exhibit, their presence, in some way, making professionals "feel good" about themselves. Lastly, they may be asked leading questions which take advantage of the service user's inexperience at handling impromptu questioning.

These sort of concerns are valid, and these practices unacceptable and exploitative. But they can also become reasons — or excuses — for not doing anything about participation.

Although it is likely that someone joining a committee or working party as a service user representative will already have some of the skills needed to participate, there may well be times when that person appears not to be making any contribution. We need to consider carefully though, whether that person makes a contribution simply by being there. The presence of a service user can say something positive about what we believe about that person's right to be involved. If we are committed to participation, then our awareness of that person's presence should have a positive effect on the outcome of discussions. If the issues discussed in this chapter have been understood and worked through, then tokenism should not be a real danger.

PROVIDING ADDITIONAL SUPPORT

It may be helpful if someone is appointed to attend meetings as a supporter for the service user — either for an initial period, or perhaps on a more permanent basis (although that may not be necessary if the service user representative becomes more skilled and comfortable in meetings).

It is important that the supporter is independent of other members of the group, to avoid any conflict of interest. For example, if the supporter is already a member of the committee or working group, then he or she will almost certainly find there are times when loyalty to the group will clash with loyalty to the service user.

In a meeting of residential care managers, it may seem logical and convenient for service-user members to be supported by one of the staff from their group home. But will that staff member always be able to put the wishes and needs of the service user first, or will they sometimes find they are supporting the wishes of their employers?

In the case of the IDC quoted above, it might have been thought practical for the People First group's Advisor to be the supporter. However, the Advisor also happens to be a member of the IDC so someone with no connection with IDC was appointed.

The supporter's job might include: helping the person get to the meeting on time, checking that they have the right papers, helping them read and digest papers before meetings, and reinforcing and developing the service user's group discussion skills.

During the meeting it is important that the supporter doesn't 'take over'. The supporter's role is to facilitate not to participate directly, to support and not supplant. It's very much a 'back seat' role with as little intervention as possible.

However, although the supporter is there primarily to support the service user, he may also have a role in helping other members of the group — for example, asking for simpler language, asking for clarification on particular points. Gradually, though, the service user should be gaining the confidence to make those requests directly.

It is important for the supporter's role to be clearly understood by all members of the committee or working group. It might be helpful to write brief guidelines — a very simple 'contract' — so that everyone knows the ground rules within which the supporter will work and their relationship with the service user.

IN CONCLUSION

In spite of all that has been written and said about 'consumer participation', when it comes to involving people with disabilities directly in the development of services, we are all beginners. Participation requires us to think about people in new ways. It challenges long-held beliefs and longstanding practices. This chapter has been concerned with how we deal with some of these issues, moment by moment, during the course of a meeting.

Perhaps the two most important words in the chapter are 'commitment' and 'listening'. Without commitment, participation is unlikely to get started. Without skilled listening, it is unlikely to develop in a way which will lead to the ultimate goal of participation — real changes for the better in the lives of people with disabilities.

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Chapter 5

COMMUNITY DEVELOPMENT: working with black and ethnic minority groups

LIZ WINN AND NIRVEEN CHOTAI

Making services more responsive to the needs of users is gaining importance on the NHS management agenda. There are a growing number of attempts to find out what users want, and to get feedback on existing services. However, many of these approaches only provide 'snapshots' of user views (eg. patient satisfaction surveys, consultation days), and there are relatively few attempts to gather information on a regular, systematic basis. Unfortunately, this means that responding to suggestions and problems may take time, or may not even be taken into account at all if they are discussed after decisions have already been made.

One of the obvious ways of making health services more responsive to the needs of users is to develop and maintain links with local community groups. Continuous contact with groups in the community can help to regularly identify what people really want from the NHS [1]. There are opportunities for gathering feedback on existing services, or on plans for future provision; and well established links may help to make future consultation exercises more meaningful and less confrontational.

Good links with community groups can also provide a useful foundation for more formal attempts to involve users in planning and monitoring service provision. This chapter examines an attempt to make services more responsive to the needs of black and ethnic minority users in Haringey health authority, by establishing formal planning forums. There are many lessons to be learnt from the example (particularly about the management and practicalities of the approach adopted) [2], but one of the most important components of the work was the groundwork done in making contact with local groups.

COMMUNITY DEVELOPMENT TECHNIQUES

A brief resume of NHS workers making contact with community groups will help to establish a context for the Haringey example.

A variety of NHS health workers have developed an understanding of the local community through community development. Health visitors, health educators, district nurses, primary care teams and community medical officers [3,4,5,6,7,8] have attempted to make their services more appropriate and accessible to users by building links with existing local groups and by fostering the development of new ones. In this way they have helped the community to define its own health needs, which then need to be fed into health authority decision-making. Making contact with the groups who have most problems with existing services means that the needs of those who often have poor access to health care can be taken into account.

This does not mean taking over (which in any case would be strongly resisted!), since many community health projects aim to equip local people with knowledge to help them make their own decisions about their lives. Nevertheless, health authority staff can have a significant input by helping groups to provide information on health and prevention and by offering advice on sources of help and support. This means that local people become more aware of their own health needs and at the same time gain knowledge of the existence (or lack) of appropriate statutory and voluntary provision in their locality.

NHS health workers adopting a community development approach combine outreach work, groupwork skills, and a great deal of sensitivity about why previous attempts to generate local interest have been unsuccessful. Methods for getting people involved and taking control themselves tend to be informal. For example, face-to-face contact with existing local groups or organisations (tenants' groups, luncheon clubs, playgroups, etc.) is one starting-point. Another might be to set up (temporary or permanent) groups or clinics in an established community venue or congregating place. Once a small caucus is established, the shape of the group and its activities can be controlled and modified by the group itself. For example, the group might begin as an educational session led by a health visitor and/or a community development worker. Over time, the focus of activity might change, eg. user-led or peer teaching, free discussion, group work, local/national campaign activity.

Using community development techniques to generate responses and statements from local groups will clearly influence the ways in which subsequent action is taken. And it is important that solutions are generated and implemented as an integral part of the community development process. Talking to groups and establishing local discussion forums is a means to an end. Resources will need to be committed and services reviewed in consultation with the same groups that identified the need for changes.

ETHNIC MINORITIES DEVELOPMENT WORKER

The best way of describing how this works in practice is to examine one example in detail. In Haringey Health Authority an Ethnic Minorities Development Worker was appointed both to implement a policy for equal opportunities in employment in the health authority, and to develop ways of making health services more responsive to the needs of the black and ethnic minority communities. The postholder was not appointed simply to provide race relations advice or information about cultural diversity to a few concerned individuals within the health authority. She was briefed to take a more proactive role by trying to involve black and ethnic minority groups in planning health services. Therefore the key component of her work had to be the development of strong and sustainable links with local black and ethnic minority groups.

The Ethnic Minorities Development Worker worked at district level and was specifically briefed to feed in user views to the formal planning and management processes. In this respect, the Development Worker's function differed slightly from community development workers and/or NHS staff working at a more local level. While locally-based workers attempt to generate and support community activity, in Haringey this was only a by-product of other work. Another difference was that the Ethnic Minorities Development Worker was purposely placed in a position that gave her influence within the health authority management structure. She was accountable directly to the District General Manager and the overall direction of her work was the responsibility of a steering group which included other chief officers in the authority, health authority members and community representatives. This direct access to people with power and the decision-making bodies in the authority is beyond the realms of most community development workers trying to bring about change at a local level. However, although these differences are important to bear in mind, there is enough common ground to be able to draw out the key characteristics and themes of community development work from this NHS example.

The Ethnic Minorities Development Worker adopted a multi-dimensional approach to facilitate the involvement of black and ethnic minority groups in planning. For example, one strategy has been to try and develop an increasing awareness amongst managers and workers of the needs of the multi-racial community they serve. In particular, the Development Worker had to explain why a 'colour blind' approach could mean that services were not necessarily accessible or acceptable to all groups in the community. Another approach has been to help managers confront their own anxieties about talking to local groups by encouraging them to make contact with groups and meet them on their home territory, thereby creating opportunities for managers to experience participation at first hand. Yet even these relatively simple approaches would have been problematic without the cornerstone of the Development Worker's job — the development of links with local groups.

With hindsight, the Development Worker can identify four distinct stages in making and maintaining contact with black and ethnic minority groups in the district.

(1) Finding out about the existence of groups

Information in Haringey Health Authority about the black and ethnic minority population was patchy and limited in scope. By tapping other sources (eg. the local authority, the Community Relations Council, a local 'umbrella group' for community organisations, the Community Health Council) it was possible to build up a picture of ethnic composition and to start to identify local organisations working with or for the black and ethnic minority communities.

(2) Initiating contact

Each organisation was contacted initially by letter, explaining the role of the Development Worker and suggesting that a meeting be arranged. Letters were followed up by telephone calls where necessary. Meetings were always arranged on the group's home territory to emphasise the Worker's commitment to joint working. Sometimes making contact highlighted the differing expectations and ways of working of NHS staff and community groups. For example, NHS workers might expect letters and messages to be answered promptly, often according to their own timetables. In reality the pace of contact-making is slow and the process is part of building trust into the relationship.

Having made contact, the Development Worker was able to gather information about the groups' purposes; whether or not they were interested in health issues; and whether they wanted to participate in planning health services. The groups responded in a variety of ways. For example, many asked for information — about availability of services (and not just about services provided by health authorities), about how services worked, about use and experience of services by people from black and ethnic minority groups and about future plans. Many doubted the sincerity of the approach from the health authority which lacked credibility in their eyes. Some were experienced lobbyists and had already made their views known. They felt that if nothing had happened before, why would it happen now? It was therefore not surprising that at this stage some groups expressed their intention to continue to work for change from outside health authority structures rather than colluding with what they saw as an inherently racist system.

(3) Follow-up work

All requests for information from the groups were followed up. In some cases material was already available and easy enough to despatch. In other cases appropriate and usable information was not available, and the Development Worker had to try and get managers interested in producing information for dissemination.

Reciprocity was considered to be a vital part of relationship-building with local groups, and this was not just limited to information-giving. Follow-up work also included service development, by feeding information into the health authority's decision-making structures.

(4) Maintaining a caucus of local support

Following initial contact with local black and ethnic minority groups, a number of organisations were identified which wanted to become involved in health service planning. The Development Worker continued to offer them support and information as well as helping officers in the health authority to set up appropriate structures for participation. Although on occasion the local groups were sounded out on an informal basis about potential changes and new ideas, a need was recognised for formal mechanisms (like planning committees, formal consultation for new developments) to ensure that the views were not requested only when expedient for the health authority. The interested local groups came to be seen as a resource to be tapped in more formal planning settings. For example, the Black and Ethnic Minority Communities Mental Health Forum was set up as a sub-committee of the District Planning Team for Mental Health. Membership included relevant health professionals together with representatives from local black and ethnic minority groups. The Forum is chaired by the chair of the District Planning Team and has a clear brief to feed policy and service development issues to that team for implementation. A similar initiative is being taken in relation to planning services for elderly people.

If all this sounds relatively easy and straightforward, it is because the inherent and consistent difficulties of working in this way have not yet been mentioned. However, the Development Worker is keen to stress that this approach to feeding in user views is not an easy option. Apart from some of the inbuilt obstacles to improving services for black and ethnic minority groups — institutional and individual racism, language, fear and ignorance — there are other difficulties and potential pitfalls which have more general relevance for health workers interested in making stronger links with their local community. It is worth looking at the particular pitfalls and problems from this example in Haringey, pulling out some of the general lessons for community development in health.

POTENTIAL PITFALLS

Community development workers, both within and outside the NHS, are generally keen to discuss some of the pitfalls of their way of working. Indeed, seemingly unimportant things can have a negative effect. In particular, the position and status of the development worker within the organisation will greatly influence the level and type of action that can be taken (if any). 'Failures' and frustrations are often the result of development workers being placed within an inappropriate setting or being outside the decision-making hierarchy. For example, concerns about GP services may remain unaddressed if the NHS development worker sits in splendid isolation in the HA community unit, rather than considering how these problems can be discussed with the Family Practitioner Committee and with local GPs.

NHS workers who develop close links with local groups are in a special position. On the one hand they have access to community knowledge and ideas about health services, and on the other they accept a responsibility to acknowledge and act on this information and so help to ensure that necessary changes are made. Unfortunately many workers in this position lack the power to commit resources or change policies in their own organisation. Yet feeding back locally identified needs will be worse than useless if this information is ignored by those responsible for planning and resourcing local health services. One way round this problem is to 'legitimise' the role of health service staff using community development approaches by incorporating their work into a district consumer strategy. Formal channels of communication and feedback need to be identified within unit structures — all the better if, in the case of the community unit, these are decentralised.

Developing good relationships with community groups requires a commitment — not only from workers directly involved but from the health authority as a whole, so that supporting and initiating local groups is seen to be a legitimate and properly resourced part of its work. NHS development workers face problems if they are constantly battling up the decision-making structures. Their relatively lowly status in many health authorities makes it difficult for them to challenge and redirect district policy, particularly if it involves negotiating with the higher echelons of decision-making. In Haringey, the Ethnic Minorities Development Worker is located where she had access to key decision-makers in the district, although this arrangement may be less appropriate where locally-based NHS development workers are working to create appropriate and responsive services in a patch or neighbourhood. The thrust here may be planning from the bottom up and so ideas and suggestions should perhaps be fed in at levels close to service delivery, eg. to locality planning teams, patch management committees, or unit management teams. It is important, however, that mechanisms also exist for bypassing this level of management when concerns are unresolved or when suggestions are consistently blocked.

Another problem faced by NHS community development workers is that they tend to be seen as experts on 'the community'. This has a number of implications: for example, they can be a very convenient stopping-place for the buck other workers are keen to pass. This is particularly true in work with black and ethnic minority groups, where often one person is implicitly deemed responsible for voicing 'the needs of ethnic minorities' (inaccurately perceived as a homogeneous group), and for making services more appropriate. If, or more likely when, the worker fails to realise these expectations, the consensus accedes to the 'impossibility' of the task and gives up trying. However, if the objectives of the development worker are integrated with those of allied workers, and they are encouraged to develop and sustain contact with community organisations themselves, then the task becomes a shared one. Setting up structures to support and expand development work will also help to reduce dependency on one or two workers who could jeopardise community links if they resigned.

In Haringey, enthusiastic NHS workers were keen to tap into networks fostered by the Ethnic Minorities Development Worker. This was encouraged — but with provisos. Staff were encouraged to work out beforehand their reasons for making contact, the possibilities for future joint work and the feasibility of service development. This was partly to avoid community groups becoming overloaded with requests for information or comment. This can cause resentment and may prevent future cooperation, particularly if the contact is badly coordinated (eg. two separate visits from members of the same planning team), or if the questions have been answered many times before — with no visible results. Sometimes staff are unaware that their professional codes and attitudes mean that groups and individuals feel *blamed* for their own (or their children's) ill health because they have 'failed' to use the services that are available to 'everyone'. Increased contact with local groups should help to shift professional assumptions so that instead of users and groups of users being perceived as problems for the health service when they do not conform to or comply with hospital and clinic regimes, the onus shifts on to service providers to develop a more flexible and appropriate service. This process obviously takes time, and staff will need advice and support from their managers (and Development Workers) in order for this type of contact with local groups to be mutually beneficial.

Sometimes, problems may arise if NHS workers rely too heavily on one group for representation and involvement. The group's views may begin closely to reflect those of the health authority or they may start to match health professionals in the overuse of health service jargon. This *may* be because a long experience of joint working has identified common ground for productive working — in which case that is hardly a problem. On the other hand, it could be the result of a gradual 'bureaucratisation' process whereby constant contact with health service providers in health service settings with health service agendas and health service timetables may have drained the community perspective from people who are by then probably unable to represent local people's views anyway. Using community development to identify community representatives is not a 'one-off' exercise. Workers need constantly to review the dynamics and interrelationships of local groups; to identify fresh fields for new work; to carry on supporting and contacting all groups within the community; and to continue to foster collective action. Otherwise the relationship may become stale and parasitic.

Finally, although some NHS workers are adopting community development approaches, there is still a need for community-led health initiatives (CHIs). The position of those CHIs working completely outside the NHS needs to be respected and understood by NHS health workers. The perspectives of CHIs offer a valuable insight into the successes and failures of local health services and this should not be ignored — but neither should their independence. NHS workers reaching out into the community need to be aware of existing work done by independent groups, to make links, and to offer channels of communication — but only if that is what is wanted. On the other hand, some community health initiatives like to keep independent bases but are closely and effectively linked to the NHS in their day-to-day work (eg. the Hackney Multi-Ethnic Women's Health Project which liaises and negotiates with the health authority via the CHC[9]). The position of these groups needs to be respected.

THE STRENGTHS OF COMMUNITY DEVELOPMENT WORK

Looking at what can go wrong when using community development techniques can help to set firmer foundations for future work, but it also has the potential for creating a negative view of the approach. Many of the strengths and advantages of community development are implicit in the above case study, but it is useful to spell them out and so re-energise failing enthusiasts!

The most obvious strength of community development is that it challenges the assumption that people do not use services or do not 'comply' with treatment regimes because they are apathetic or contrary. By working with groups who may previously have underused services, the emphasis shifts to orienting services towards the needs of the community rather than the other way round. So, for example, if parents and children miss appointments for clinics and tests, the onus rests on the service provider to examine obstacles to using the service. By establishing relationships with local groups and talking about previous experiences, a range of problems and blocks may emerge. These might be personal, professional, racial or social (eg. an absence of women doctors, a racist receptionist). Or it might be that something perceived as important by health workers is considered to be irrelevant by potential users (eg. routine checks for head lice). The next move for health workers is to discuss and negotiate with members of the community how the service can be provided more appropriately. In Haringey, many of the changes that were made were often relatively small-scale, eg. the increased availability of religious ministers for a variety of ethnic and cultural groups in hospital, which was found to be a major concern of elderly people from black and ethnic minority groups. However, the accretion of many small changes can add up to significant attitudinal changes over time, and so although progress may seem slow, the consolidation of activity over a number of years (and this is the timescale) can add up to major changes to services.

The second major advantage of working to build relationships with the community is a practical one. It has great potential for tapping information and skills in the local community. A common complaint about health service management is that decisions are made in an undemocratic way followed by a tokenistic exercise of consultation which is cranked into gear in order to show willing. Even if groups can face wading through lengthy documents and reams of tables, they may feel justifiably pessimistic about the chances of their comments having any impact on the proposed service. If those being consulted have serious reservations about the overall *aims* of the service under discussion, it will be unquestionably too late to try to change the direction at such an advanced stage. The response from those consulted is therefore likely to be hostile and destructive. By involving community groups at the *beginning* of the service development/review process, there is a good chance that comments will be constructive, that a collaborative and mutually beneficial relationship will develop, and that the service ultimately provided will be appropriately designed and delivered.

Community development offers a sensitive approach to identifying local needs and concerns. Some of the macro-measures of the needs and characteristics of a given population (eg. census data, General Household Survey) will not necessarily show up subtle changes and influences. One of the best (or worst) recent examples of this has been the failure of many London health authorities to respond to the increasing numbers of homeless families temporarily 'housed' in bed and breakfast accommodation in their districts. Census data is completely inappropriate, and even daily administrative information about the movement of families is often uncoordinated and poorly disseminated. Health authorities which have attempted to provide appropriate services have relied on detective work and contacts with community and support groups to identify the special health needs of homeless families. Using health worker contacts with community groups can be a valuable aid to detecting future patterns and needs long before (outdated) census data can, and long before problems reach crisis point.

There are also 'fringe' benefits for NHS staff who increase their contact with the community. For example, including users on planning teams or other decision-making bodies potentially adds a whole new range of ideas about service delivery and approaches to tackling problems. 'Us/them' attitudes are understood and challenged and the balance of power between users and providers can potentially shift in favour of users. Staff develop new skills to cope with the new relationship and are more confident about talking to their managers about ideas for changing the way services are provided. In other words, the processes as well as the outcomes of building links between professionals and local people are in themselves valuable tools for changing attitudes and relationships.

Finally, with the recent trend towards the decentralisation of community health services, and a recognition of the need to plan locally relevant services, community development offers a valuable tool for the targetted identification of local needs and the generation of ideas for service development and review. In other words, reaching out to the community and taking a proactive stance towards consultation and user involvement will reveal an extensive amount of local information which can be used to develop more appropriate local services.

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Chapter 6

CITIZEN ADVOCACY FOR PEOPLE WITH DISABILITIES:

KATE BUTLER AND AMANDA FORREST

A citizen advocate is an independent and competent volunteer (usually described as the 'advocate') who vigorously represents the interests of another person (usually referred to as the 'partner') as if they were their own, and works to safeguard that person's human and legal rights.

Another definition of a citizen advocate is made by O'Brien [1]:

> *A valued citizen who is unpaid and independent of human services creates a relationship with a person who is at risk of social exclusion and chooses one or several ways to understand, respond to, and represent that person's interests as if they were the advocate's own, thus bringing that person's gifts and concerns into the circle of ordinary community life.*

This chapter offers a brief introduction to citizen advocacy, based on the authors' involvement with a citizen advocacy office for people with learning difficulties. It discusses the reasons why citizen advocacy has developed; key principles in CA; how CA schemes are developed and run; the functions of the advocate; and common difficulties which occur in setting up and running CA schemes.

WHO NEEDS CITIZEN ADVOCACY AND WHY?

Citizen advocacy, both in Britain and elsewhere, has developed largely in response to the common experiences of people with learning difficulties, many of whom experience considerable disadvantages and impoverished lifestyles. However benign the intentions of service providers, there is an increasing awareness of the dehumanizing and stigmatising effects of being entirely dependent on services which can easily leave people with little control over their own lives.

Even today, the majority of services to people with learning difficulties are physically and socially segregated from the rest of the community. Many service users spend all their time with people who are paid to be with them, with few opportunities for making ordinary friendships and relationships. On top of these disadvantages, people with learning difficulties rarely have the chance to participate in the development, management and delivery of the services on which, in many cases, they are largely or wholly dependent.

Current development in health and social services in Britain also reinforce the need for citizen advocacy. Harris [2] has identified four major trends in service delivery which may have a negative impact on the individual consumer: the increasing complexity and fragmentation of services and the emphasis on organisational structures (shifting away from a focus on the individual); the introduction of information technology which raises issues of privacy; the greater emphasis on cost-effectiveness which may override issues of service quality; and an emerging consumer movement highlighting the dissatisfaction of many service users.

Citizen advocacy is one way in which ordinary citizens can become directly and personally involved with someone who is devalued. As more people take up this challenge, communities may learn to be more responsive to, and responsible for, others who have increasingly run the risk of being seen solely as the natural recipients of professional expertise. By bringing things back to an individual level the stranglehold of health and social service provision can be untied, and the balance of power restored.

Potentially citizen advocacy is a powerful means of addressing these fundamental disadvantages and inequalities. Advocating for and upholding the basic human rights of individuals underpins the values and ethos of citizen advocacy.

THE DEVELOPMENT OF CITIZEN ADVOCACY SCHEMES

Drawing on the experiences of more than 200 well-established CA schemes in the United States, Canada and Australia, the 1980s have seen the gradual development of citizen advocacy offices in Britain. At the time of writing (January 1989) there are about a dozen CA schemes in operation — the majority for people with learning difficulties, but one or two for people with long-term mental health problems. Some are working with people living in hospital, and others with people who are in the community. Most offices recruit partners (i.e those needing advocates) from a variety of living situations.

There are a number of different stages involved in setting up a citizen advocacy office, but before moving on to look at what these are, it is important to first describe some of the key principles involved in citizen advocacy, which need to be thoroughly understood before a CA office is established.

Harris [2] and Carle [3] both identify a number of key elements in successful citizen advocacy.

AVOIDING CONFLICT OF INTEREST

The notion of conflict of interest is the central issue in the development of citizen advocacy. Health and social service provision is constantly faced with conflicts of interest. However, it is important to understand that this does not merely refer to the personal characteristics of service providers but also to inbuilt contradictions in service provision. Conflict of interest is present in various forms. Firstly, what is good for the service may not necessarily benefit the consumer, e.g a drug regimen that conveniently makes someone 'easier to handle'. Secondly, front-line workers may have different motives, attitudes and interests from those in policy-making positions, e.g managers may have incentives to resettle people from hospitals; workers may be very anxious about the implications of this for job security. Thirdly, most services have resource constraints and the competing interests of different consumers have to be prioritised. Additionally, service systems can break down if those working in services are unable to handle the stress of their jobs. Sources of conflict of interest result in compromises and trade-offs, and where interests do clash, the consumer is usually severely disadvantaged. Citizen advocacy is one way of confronting the issue of conflict of interest.

The individual advocate must be completely separate from — and independent of — any direct service provision used by the person with disabilities in order to avoid conflict of interest. The advocate must be able to act without any concerns relating to his own job, career or the needs of the service used by his partner. The advocacy office likewise should be wholly independent of service-providing agencies in terms of its funding base, its administration and location (this issue is discussed in more detail below).

ONE-TO-ONE RELATIONSHIPS

Although organisations and individuals may undertake group advocacy on issues such as welfare benefits or legislation, the one-to-one relationship of advocate and partner is central to citizen advocacy and enables the advocate to use his time and energies in improving the life of a particular individual. It also provides a strong counter-balance to the general tendency of services to view people with learning difficulties as a homogeneous group rather than as individual human beings with their own particular likes and dislikes.

LONG-TERM AND CONTINUOUS RELATIONSHIPS

Although not every single advocate-partner relationship will be a long term one, the agency should be striving to support as many long-term advocacy relationships as possible. Many people with learning difficulties, particularly where they have spent all or most of their lives in hospitals or other service settings will have had very few experiences of long-term relationships; staff move on, are promoted or leave the service. A citizen advocacy relationship should strive to be long-term and one which may even last a lifetime.

THE ADVOCATE'S COMMITMENT TO THE INDIVIDUAL

The citizen advocate's primary loyalty is to their partner, rather than to the CA office. Advocates are not 'employed' by the office, and being an advocate should not be viewed as a job. Advocates do not receive payment for their involvement with a partner.

SETTING UP A CITIZEN ADVOCACY OFFICE

An effective citizen advocacy agency will be founded on the basic principles set out above, underpinned by a strong ideological commitment to citizen advocacy on the part of all those involved.

Although there is no single format for starting up a CA office, the approach described here draws heavily on how they have evolved in the USA — and, more recently, in Britain.

It is advantageous to establish a core group of local people committed to the development of local roots in the community. A core group should be striving to achieve and maintain a focus on citizen advocacy and to support ongoing action. O'Brien [1] argues that there are significant numbers of ordinary citizens, who, for various reasons, are motivated to become personally involved with people with disabilities — either as advocates or as members of the core group.

Every effort should be made at this stage to recruit individuals with a variety of perspectives and local connections, who can also bring to the group the necessary financial, administrative, and managerial skills to develop and manage a citizen advocacy scheme.

It is important that in all stages, but especially in the early stages of an advocacy group, energy is invested in building up links with local community leaders. In this way, the status and influence of the agency is strengthened.

THE PATH OF CITIZEN ADVOCACY

Forrest [4] has identified four stages involved in bringing together advocates and partners.

(1) Identifying people with disabilities who may be: lonely, isolated, excluded, denied services, lacking opportunities in their lives etc.

(2) Inviting members of the community to become involved with a person with disabilities; to become friends with them, speak up on their behalf, represent their interests, include them, and seek out opportunities of enriching and enhancing their life.

(3) Introducing the two people to each other as potential advocate and partner, enabling them to spend time together, getting to know and respect one another.

(4) Helping the advocate to understand their partner's situation by introducing them to the principles of citizen advocacy, describing their partner's life situation, looking at possible directions and options for now and the future, together with their partner.

In addition to this process of identifying people needing advocates, recruiting and training those advocates, and matching advocates and partners, the advocacy agency will have a number of other tasks including: providing ongoing support and back-up to advocates through information dissemination, meetings, discussions, etc; developing the knowledge and expertise of the staff and management committee; developing further useful contacts in the community; identifying others who will join the organisation as committee members, advocates, or general supporters.

FUNDING CITIZEN ADVOCACY

Funding which is both independent and long-term continues to remain an ideal rather than a reality for most schemes, the majority of which receive health or local authority monies. The dangers of finances with strings attached to service providing agencies are clear, and repeated funding crises divert energy from creating and supporting advocate-partner relationships. Schemes which do not have financial independence need to minimise the constraints attached to such funding to ensure that the creation and support of citizen advocacy relationships is possible. Efforts should also be made to increase the proportion of funding from alternative sources. At the same time, CA offices need to be conscious of the imagery attached to various funding sources and methods. Do fundraising techniques suggest that citizen advocacy is a charitable activity or that it is concerned with human rights? Language and visual images should portray people with learning difficulties in ways which are positive and image-enhancing.

The main problems with funding in the UK so far have centred on the difficulty of obtaining long-term secure funding so that both the staff and the management committee can concentrate on building up a good CA service rather than lurching from one financial crisis to the next.

WHAT DO CITIZEN ADVOCATES DO?

The stage of creating citizen advocacy relationships is often the most exacting for an advocacy agency. The diversity of advocacy roles and the advocate's ability to carry them out depends upon the capacity of the organisation to adhere to and develop the principles of advocacy. The range of roles which an advocacy office conceptualises and plans for as it recruits, matches and supports advocates is perhaps the single most powerful determinant of the scheme's long-term success.

Although individual advocates will choose the investment in the relationship they wish to make, and, together with their partner, will determine the direction and content of their relationship, in practice, most advocates will choose from within a range of options (e.g from neighbour to spokesperson) defined and supported by the advocacy office.

Those who have developed the concept and practice of citizen advocacy have identified two main strands in the advocacy relationship: the *instrumental* and the *expressive*.

The *instrumental* role can best be described as 'problem-solving', where the advocate might help with such matters as access to dental or other health services, obtaining benefits to which their partner is entitled, or representing the person at an individual programme planning meeting and speaking on their behalf.

The *expressive* role involves meeting the other person's needs for affection, warmth, love and support — in other words meeting their basic emotional needs. As well as offering ongoing friendship, this might involve the advocate sharing family and friends, offering support in a crisis and celebrating significant anniversaries such as birthdays and religious festivals.

An advocate may be involved in fulfilling one of these roles or both.

Experience suggests that most citizen advocacy offices tend to have an emphasis on long-term informal advocacy with modest demands. Whilst this is perfectly legitimate, it has narrowed the range of advocacy roles. Citizen advocacy schemes need to develop policies and strategies that allow for a wide variety of advocacy options. The crux of citizen advocacy lies not merely in the differences and variety of roles, however, but in the innovative nature of the relationship between the devalued person and the valued person, the advocate.

THE ACHIEVEMENTS OF CITIZEN ADVOCATES

As a member of a partnership enabling people to have an effective say in how their lives are run, advocates are asked to view the world through their partner's eyes and to ask themselves: "Would I want....? Would I put up with....?"

Independent advocates representing their partners' interests have opened doors for everyday opportunities in a variety of ways. They have:

- helped a couple get married, despite opposition from people working in services;
- pushed for an elderly lady to receive ophthalmic treatment, after years of waiting for an operation;
- helped a young man join and become involved in a Country and Western club;
- assisted a man in hospital to gain control over his own income;
- launched a public campaign to ensure an isolated man received appropriate and necessary support from a range of services.

DIFFICULTIES ARISING IN CITIZEN ADVOCACY

Developing and maintaining autonomy

Although this issue has already been touched on above, it is worth returning to at this point because it can cause some of the greatest difficulties for CA projects.

The management group must be able to act independently when formulating and implementing policies relating to such matters as recruiting partners, or recruiting and supporting advocates.

But even before this stage is reached, the core group (see above) must be able to develop its philosophies and operating principles separately from those of established services. This can be hard to achieve where there are radical and enlightened service managers who wish to support citizen advocacy and may not see the necessity of the core group — and eventually the project itself — remaining completely separate from services.

In practice, advocacy schemes in Britain have tended to come into being at the behest of service-providing agencies, yet still hoping to implement their aims and objectives independently of those organisations. In practice, an uneasy truce has often evolved between services and advocacy agencies.

Professional attitudes

As with any movement which attempts to redress inequalities and shift the balance of power, opposition is likely from at least some of those who have a vested interest in maintaining the status quo. Although some staff in services have welcomed the advent of citizen advocacy, others have found various ways to oppose its aims. Opposition may be openly expressed — "these people don't need friendships, they have us" — or may manifest itself in making life difficult for the advocate — for example, finding reasons why the advocate should not visit their partner too often or on a particular day.

Consequently those involved in citizen advocacy have to be willing to negotiate rights of access, counter arguments of possible exploitation of people with disabilities by volunteers, resist attempts to absorb advocates into service structures and provision, deal with misinformation and face up to the stress of possibly being ridiculed. Standing alongside the oppressed or disadvantaged requires strength and commitment.

Recruiting advocates and developing an active management committee

Recruiting advocates can be a slow process and offices may find it difficult to recruit enough suitable and active management committee members. They may have problems tapping into the local groups and networks in order to build up an agency which has strong roots in the life of the community.

It can sometimes help if staff are appointed who are a part of the local community and who are already actively involved in community activities in some way.

Avoiding further segregation

In the UK, most citizen advocacy offices have focused exclusively on people with learning difficulties. The ultimate irony of this approach is that it may perpetuate the separation and labelling of the very group it was set up to de-segregate and de-label. There is also a danger that binding associations develop between the service world and the advocacy group if the group shadows services through adopting the same structures, terminologies and approaches used by services. For example, in its early years, Sheffield CA office was perceived as an extension of services for people with learning difficulties. 'Referrals' (service terminology) were automatically accepted by the office if they were from service workers; and members of the core group were often themselves involved in planning and management. In these situations the important position of independence is undermined.

There are therefore two lessons: first that separating out particular groups of service users may create further stigma; and second, that independence for CA offices can be threatened in quite subtle ways — including by sharing the terminology of service providing agencies.

CONCLUSION

There is no doubt that interest in CA is rapidly gaining momentum and offices are being established throughout the country. It is important that care is taken to ensure that the underlying principles of CA are put into practice, otherwise there is a danger that initiatives may simply perpetuate the problems of people who have been kept dependent and who are devalued by society. In our view, the keys to successful CA are: independence from service provision, long term commitment and the development of one-to-one relationships. Understanding the complexities as well as the benefits of CA may be one of the most important steps towards independence and strength for those who are devalued members of the community.

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Chapter 7

MENTAL HEALTH SELF-ADVOCACY:

PETER CAMPBELL

THE ROOTS OF SELF-ADVOCACY

Although current developments in mental health self-advocacy may differ in form from earlier initiatives, self-advocacy and opposition to the psychiatric system are not new phenomena. Any system like psychiatry which can have such an intensive and extensive impact on people's lives will arouse opposition and protest from those whose experiences are harmful or generally negative.

Since the creation of the asylum system over 150 years ago, which nurtured psychiatry and shaped the development of modern mental health services, there have been protesters. The self-advocate of today shares common ground not only with the Mental Patients Union of the 1960s and early 1970s, but also with the Alleged Lunatics Friends Society of the 1860s and the protesters of the 1940s and 50s.

SELF-ADVOCACY AND THE ANTI-PSYCHIATRY MOVEMENT

Since the late 1960s, there has been a tendency to define any coherent opposition to the psychiatric system as being part of the 'anti-psychiatry' movement spearheaded by such figures as R.D. Laing, Thomas Szasz and David Cooper. But the self-advocacy movement cannot be seen as totally synonymous with this movement. There are common ideological links, but there is a much broader range of ideologies within the self-advocacy movement. Those involved in self-advocacy, for example, hold a range of views on whether 'mental illness' exists as such, and whether or not collaboration with the psychiatric system is desirable. In addition, the ways that self-advocacy groups are working are often far more pragmatic than in the anti-psychiatry movement. In a sense, mental health self-advocacy could be characterised as reformist, seeking ways of changing and improving the existing systems, rather than taking up dogmatic ideological positions.

The common bond that links recipients who speak out and act now with those who did so in, for example, the Mental Patients Union, is rooted in common experience. Personal witness is a major impetus behind self-advocacy. Personal experience of a system which too often fails to meet human needs and employs procedures which leave traces of unforgotten anger and distaste lead to a deep-seated and emotionally-rooted desire for change which has nothing to do with dreams of efficiency of a cost-effective management structure — the perceived approach of many managers in service-providing agencies. It is the shared experience of service users which motivates action for change.

THE CONTEXT OF SELF-ADVOCACY TODAY

Mental health self-advocacy in its present form may owe a great deal to the particular and peculiar circumstances of the 1980s: the growing fashion for consumerism within the NHS; the increasing self-doubt within a psychiatric system confronted by major changes in its *locus operandi*; a growing number of mental health professionals with a stake in services; and — finally — the existence of cohorts of service users who have persistently been treated as second-class citizens. Service recipients, labelled by society as 'mentally ill', have an unenviable status. Whether one considers this group to be oppressed or not, it is fairly clear that its members are devalued, ascribed attributes which are predominantly negative, and discouraged, either openly or covertly, from full participation in equal citizenship.

THE GOALS OF SELF-ADVOCACY

It is important to recognise the extent of the goals of self-advocacy. Bluntly put, self-advocacy is not only about tinkering with the National Health Service. Of course that matters — and changing the shape of existing and future mental health services is a major concern of recipient groups — but self-advocacy has to be seen in a wider context. Self-advocacy must also direct its efforts towards improving the status of service recipients in society at large. The psychiatric system feeds into society's prejudices by segregating service recipients, and promoting negative stereotypes involving 'illness', 'disease', and making people powerless to control their own lives. But oppression occurs outside the psychiatric system as well.

There are areas outside the NHS which discriminate against service recipients — in housing and employment, for example. Service recipients are also disqualified from insurance protection, and sometimes from voting. Indeed, the whole range of 'not havings', which are part of the lives of service recipients, are the legitimate concerns of self-advocacy.

Self-advocacy is to do with power and powerlessness, with people regaining control over their own lives — something which many recipients believe the psychiatric system denies them, however ostensibly caring mental health services may be. But recipients who become self-advocates also recognise that without a wider change in societal attitudes and practices, the so-called 'mentally ill' will remain a devalued element in society. Society will continue to ignore or fear them, sometimes despise them, and only focus on what they think recipients cannot be or do rather than fostering and supporting their abilities and achievements.

A WORD ABOUT TERMINOLOGY....

Before going further, it may be useful to raise the issue of terminology. In this chapter, the term 'recipient' has been used to describe those who either currently or formerly have used mental health services. The use of 'recipient' is deliberate, because the author feels it best conveys the essentially passive relationship they have with those who provide services. It also reflects their frequent lack of real choice and their minimal involvement in shaping the system.

However, it should also be pointed out that not everyone would agree with this particular choice of terminology, and no claim is made that this is a universally accepted term. One of the difficulties is that much of the language used has not been chosen by those it describes. It should not be expected that when people do assert their power and choose terms of self-description they will necessarily arrive at an agreed term. Although it may be untidy to have numerous descriptions — consumer, user, recipient, system survivor — this may be a truer reflection of the complicated realities which other (externally sanctioned) labels such as 'mentally ill' have previously concealed.

The term 'self-advocate' has advantages and limitations. On the one hand it is linked with, and should be the matrix for other advocacies in the field — e.g legal, professional. On the other hand, it seeks to encapsulate relatively new developments which are actually quite diverse. The danger is that this diversity will be given a spurious sense of coherence, and the full potential and the contradictions of what is in essence a grass-roots initiative will be overlooked by the anticipations and mind-sets of those who are not recipients. There is a danger that if definitions are too tightly drawn too early on, outsiders may end up setting the agendas and marking out the boundaries of what is and what might happen.

GROWTH OF SELF-ADVOCACY GROUPS WITHIN THE UK

At the time of writing there are at least 35 mental health self-advocacy groups in the United Kingdom. Four years ago there were half a dozen. Although none of these groups are very large and all face the usual problems of small, minimally-funded action groups, they are part of an increasing wave of activity by recipients. More people using mental health services are realising that they have a right to participate, that they have a valuable contribution to make and that working for change is a real possibility. Regardless of the detail of what is actually happening and how much is being achieved, the willingness of recipients to start working together symbolises a change in self-attitude. Simply using, receiving or consuming the National Health Service may no longer be a ritual conducive to adult citizenship.

TYPES OF GROUPS

A number of distinctions can be made between groups which are generally described as mental health self-advocacy groups. One distinction is between groups which are directly connected with service provision and those which operate outside the system as pressure groups. The former tend to have a different flavour, not necessarily because they are linked to service provision, but more because they tend to meet more regularly, be generally more organised, and to have more stable sources of funding. Their particular status, however, does not necessarily exclude them from campaigning and other pressure group activities. However, although most groups are not directly involved in service provision, those that are have become well known and have certainly influenced the development of self-advocacy up to the present; some of them are briefly described below.

Link (Glasgow Association for Mental Health) are a group that made an early impact. Link now runs a number of evening social clubs in the Glasgow area which are organised by recipients who had recently gained control over their own finances.

Another well known group is **Contact**, which is based in the Chesterfield Community Centre and which demonstrates the self-advocacy principle of acting on one's own behalf in relation to a service. Contact is sponsored by Derbyshire County Council through North Derbyshire Mental Health Services Project and is a social support group. Members, who run the project, have a weekly group meeting and an elected committee (consisting of four men and four women) is responsible for such matters as negotiating funding with the County Council.

The **Women and Mental Health Network** in Bristol was established with a view to providing services which would supplement existing provision or offer an alternative. Theirs is a more independent structure and their successes so far have demonstrated the possibilities of women defining their own needs and working together to meet them. Mental health projects for women in Bristol now include: **Womankind**, a mental health self-help project running weekly drop-in groups, and offering information and education resources; **Missing Link**, a housing project for homeless women; and **Bristol Women's Crisis Service** which runs a weekend telephone helpline.

The more common model can best be described as the local action group; indeed, some actually include the words 'mental health action group' in their title. These tend to be relatively small groups with a regular core membership of up to 20. Most have regular monthly meetings and operate with minimal financial resources. Although they share the common purpose of promoting the recipient perspective in the psychiatric system, their particular activities are shaped by local priorities. Thus while Camden Mental Health Consortium has attempted to influence the planning process and has published *The Consumer Viewpoint* on services in Camden, Hackney Mental Health Action Group have published a *Charter of Rights*. Ealing Mental Health Action Group has worked to highlight the wide variations in the use of ECT in their area. Mental health self-advocacy is notable for the diversity of its activities.

One further type of group which has developed is the Patients Council Support Group whose activities are described more fully elsewhere in this anthology.

Finally, there are two national campaigning groups — Campaign against Psychiatric Oppression (CAPO) and the British Network for Alternatives to Psychiatry. Although both groups are London-based, their views have been more widely promoted around the country. They have addressed broad and controversial issues such as compulsion in psychiatry and the misuse of certain treatments. Both organisations are important because they link present-day action and earlier movements such as the Mental Patients Union. The British Network is also part of an international network seeking to challenge psychiatric orthodoxies. In a real sense, both groups have provided a seeding-ground stimulating the growth of self-advocacy in Britain.

SURVIVORS SPEAK OUT (SSO)

Since January 1986, the development of groups and the increase in recipient action has been facilitated by this national organisation. SSO was established following the Mental Health 2000 conference at Brighton where recipients from England and Wales were conspicuously absent. As a result of this, funding was secured to enable people from the existing self-advocacy groups to meet together over a weekend and discuss better ways of communicating with each other and of promoting the voice of recipients on future occasions. This meeting led in turn to twenty people holding a further meeting in January 1986, at which SSO was founded. Its main aims have been to improve communication between those involved in self-advocacy through personal contact and written information, and to promote the development of self-advocacy.

In September 1987, SSO organised a national conference of 'system survivors and their allies' which took place over a weekend in the Peak District. This was the first national conference for recipients for many years and proved to be a springboard for increasingly widespread activity by recipients during the following year. SSO's membership has grown from 20 in March 1986 to over 250 members in June 1988. But even so, it depends entirely on the energies of volunteers and operates within stringent financial limitations.

ISSUES IN SELF-ADVOCACY

The present character of SSO highlights a number of important issues in mental health self-advocacy.

The organisation is not the national voice of recipients, self-advocates, or consumers. Currently there is no such national voice — partly because most developments so far have occurred locally, but partly because the scarcity of time, energy and money makes the task of setting up a representative national structure quite daunting. But it is also because of real difficulties with the concept of representation. After years of having other people speaking for them, telling them what their lives were about, and suggesting that they were not competent to act or speak for themselves, recipients are cautious about representing others too glibly. They have been at great pains to emphasise when they are speaking as individuals, and when they are not, to be clear about what group they do claim to represent. They have tried to make it clear, for example, that self-advocacy groups largely consist of people who live most of the time in the wider community and that they cannot, therefore, speak for those who have spent most of their lives in institutions. (Even Patients Councils Support Groups, which are set up to facilitate the development of Patients Councils in institutions, by and large seek to facilitate and support the members of these Councils, rather than speak on their behalf.)

This issue has led to real and unresolved problems. Most of the people with whom self-advocacy groups come into contact see themselves as being able to speak on others' behalf (often because of the position they hold in an organisation or agency). Groups and individuals who refuse to adopt the same approach may find themselves being invalidated. On the one hand, there is an implied accusation of dishonesty, on the other hand though, the suggestion that criticisms and proposals can only be valid if those presenting them are blessed with a charter of representativeness. It seems the news is only true when the bearer is wearing the right badge. If those who control the system value representativeness so highly, then they should provide the structures and resources to allow it to happen. Self-advocacy groups should not be expected to build representative mechanisms by themselves, while those who have the power to shape services twiddle their thumbs and make disapproving noises. It is cynical to dismiss the contribution of self-advocacy on the basis of criteria which cannot be met. Self-advocacy and democratic representation are connected but they are not identical. Playing them off against each other should be recognised for what it is: a strategy for inaction.

A significant feature of SSO is that its membership includes both 'survivors' and 'allies'. In other words, it is non-separatist, and in this way differs from mental health self-advocacy in most other countries. Although not all local groups in Britain are non-separatist, and in those that are there are varying degrees of alliance, the general atmosphere is mainly one of 'working together'. Mental health workers have played a significant role in enabling groups like SSO to get off the ground, and they continue to have a significant role in a number of well-established groups.

Forging alliances with mental health workers can have certain advantages for recipients. They may be able to tap into the skills which workers have acquired through training; workers are more likely to know their way round the system than recipients. Finally, workers may lend credibility to a movement, most of whose members are considered second-class citizens in society's eyes.

Alliances with workers may strengthen self-advocacy, but they can create problems too. Self-advocacy is about empowerment or re-empowerment of recipients, and workers as a group are deeply implicated in that original process of disempowerment. But there are practical difficulties too. The skills and training, and the self-confidence of workers can easily lead them to dominate the group — however unintentionally. Recipients, with their particular experience of the psychiatric services may also find it hard to trust professionals. Other emotions can be powerfully present in these alliances — fear, guilt, anger, and resentment can all surface. It is significant though that these concerns are being voiced and that co-operation is very much a live issue.

Commenting on the unique situation in Britain, Judi Chamberlain writes: "both psychiatric survivors and radical mental health workers propose an ideology of empowerment and autonomy; it remains to be seen if these two groups can overcome their historic differences, including class and power differentials, to promote these ideals for all".* The next two or three years will be crucial in this respect.

The issue of credibility is also very much on the agenda. Unless the professional groups who plan, manage and provide mental health services accept as valid the evidence put forward by recipients, self-advocacy has a limited future. We have reached a position now where recipients' views are listened to , they are regularly invited to speak at conferences, and will often be consulted on a range of issues. But it is not so clear what weight will be attached to their contributions — in short, whether listening will be translated through hearing into doing. There are real problems here. Consultation is still too often carried out as an afterthought. There are also grounds for suspecting that in some instances the recipient view may now be sought in order to give important considerations an acceptable profile rather than because of any real commitment to full recipient involvement.

As discussed above, representativeness is seen as a major issue in some quarters and its absence may even lead to recipients' views not being seriously considered. But their evidence may also be discounted for other reasons; it may be described as 'unscientific' or 'lacking in objectivity', for example. While it may be unreasonable to claim that recipients have access to some 'higher truth' by virtue of their personal experience of mental distress, it is important that the status of recipients' evidence and proposals is clarified.

If a group spends a year working on a critique of services to present to management and it is then discounted because the evidence is considered to be in some way deficient, then a whole area of recipient activity is called into question. This in turn raises the wider issues of how groups can decide which activities are worth continuing and which may be leading up

* From On Our Own: patient-controlled alternatives to the mental health system. MIND, 1988.

blind alleys. If presenting evidence or writing critiques are to be ignored because they are not considered on a par with professionally accredited research then this needs to be made clear. It is time to discover how the work of recipient groups is valued by those with influence in the psychiatric system. If this work is considered deficient in some way, groups need to discover precisely why.

THE FUTURE OF MENTAL HEALTH SELF-ADVOCACY IN THE UK

The growing number of recipients prepared to work for change is of more than passing significance but the future of mental health self-advocacy is not assured; we are only just moving out of the honeymoon phase. The possibilities and limitations of recipients acting as self-advocates are by no means clear. But there are also two practical considerations to be taken into account.

The first of these is money. In the last few years, a remarkable amount has been done with very low financial resources. Groups, and in particular, local action groups, have operated with virtually no finance; but for how long they can, or indeed ought to continue is open to question. The quality of much of the activity is severely circumscribed by lack of resources. For example, recipients are increasingly involved in training events for groups of workers, yet lack of resources prevents them from developing training skills or creating the presentations or workshop packages that would make their training input properly effective. If self-advocacy is considered to be a 'good thing' then sooner or later someone is going to have to come up with some financial support. It is quite unrealistic, for example, to expect Patients Councils to succeed on minimal finances. They are involved on an intensive basis in visiting wards, facilitating ward meetings and providing administrative back-up for hospital-based Patients Councils. All this work is currently carried out largely by volunteers but if more PCSGs are to get off the ground, proper funding is essential. A co-ordinated approach to funding is also needed to avoid the present situation of different groups aproaching the same restricted range of funding bodies. Funding is one indication of a commitment to change. Its comparative absence from the arena of mental health self-advocacy is of some significance.

This leads directly to the second important consideration — that of intentions. How much is really up for change? How far are those with power prepared to share it with recipients? And how compatible is the government's concept of consumerism with the developing philosophy of self-advocacy? Any answers to these questions are bound to be cautious at this stage.

In terms of moves to greater power-sharing there are certainly many mental health workers who are prepared to share their power, but many more are indifferent and more still are actively hostile. Certain powerful groups appear to see no real role for self-advocacy and, regardless of individual intentions, the complexities of a closed bureaucratic system make it hard for outsiders to make any impact. By and large it is proving very difficult to penetrate through tokenism to a truly meaningful involvement. All the realities tested out through the month-to-month work of recipients confirm the capacity of the psychiatric system to resist or deflect change.

But of potentially greater concern is the real doubt that at the highest levels there is any coherent response to mental health self-advocacy. The DHSS and policy documents such as the Griffiths report place considerable emphasis on consumerism but have little to say about how structures need to be altered to incorporate real consumerism. Were the government even to embrace consumerism though, there are real doubts (already mentioned above) as to whether 'consumerism' is really the same as 'self-advocacy'.

Despite these not inconsiderable difficulties, the potential for developing self-advocacy should not be discounted. The situation in the UK is fluid. Any assessment of the achievements of self-advocacy should recognise that developments in this country are comparatively new. In countries like Holland or the United States the movement has been established much longer. There are encouraging signs in the UK. There are now Patients Councils in at least 10 areas, from Portsmouth and Southampton in the South to Gosforth and Ashnington in the North East. In Camden and Nottingham, recipients are playing a real part in planning and running day services. Across the country there seems to be a positive response to the concerns expressed by recipients about such issues as lack of information on drug treatments and the need for 24-hour resource centres. Some groups of workers — notably community psychiatric nurses and social workers — are beginning to involve recipients in their training programmes. Even if structures remain largely unchanged, there are signs that attitudes may be changing.

The author has tried to place mental health self-advocacy in a realistic perspective. Half a dozen years ago, action by recipients was virtually non-existent. The most remarkable achievement now is that almost all the self-advocacy groups established in the last four years are still in existence, and their overall number is growing steadily.

The response from the most influential groups within the psychiatric system has so far been lukewarm. Whether or not this remains so may well influence the future direction of self-advocacy. If the response becomes more positive then recipients may collaborate and work with the existing structures. Otherwise they may adopt an outside position, offering more independent criticism and possibly also alternative services.

Even if there is an official rebuff from those within the psychiatric system, self-advocacy will not go away. Those who have not experienced the debilitating effects of the psychiatric system for themselves — the isolation, the invalidation of areas of experience, the frustration of creative potential — may easily underestimate the positive impact on recipients of being able to work together. Self-advocates will not go back into the closet.

At this early stage, what is needed above all, is a recognition that self-advocacy is about empowering people. Success will not lie in seeing how much we can change by 1992, but by giving recipients the time and space to work together and define their own goals.

Chapter 8

USER GROUP INVOLVEMENT:

COLIN GELL

One important strand in the development of self-advocacy by people who use mental health services in Nottingham is formed by the Nottingham Patients Council Support Group and the individual councils for which it acts as an umbrella organisation.

Like several other self-advocacy initiatives which have sprung up during the 1980s, NPCSG offers mental health service users the opportunity to exercise some influence on the way those services are managed and delivered and may enable them to exercise a greater degree of control over their own lives.

The catalyst for the development of the NPCSG was a major international mental health conference held in Brighton in 1985 when members of the Dutch Patients Council Foundation and the Advocate Foundation were present and a video describing their work was shown to conference delegates.

THE DUTCH PATIENTS COUNCIL MOVEMENT

Patients Councils (or Committees) were established in Holland in the early 1970s following complaints by some service users about the quality of their mental health services. Although these initial complaints focused mainly on day-to-day issues such as poor quality catering and inadequate day-time activities, the Dutch user movement has grown to the point where each of Holland's forty-four psychiatric hospitals is now required to have a Patients Council with whom the hospital's management must consult on a regular basis. Each Council has a support worker who acts as the main point of contact and is responsible for developing the Council's activities.

DEVELOPMENTS IN NOTTINGHAM: AUGUST 1985 — MARCH 1986

Although British service users were notably absent from the 1985 Brighton conference, two mental health workers from Nottingham were present and, impressed by what they heard of the Dutch patients movement, they resolved to attempt to start up a similar initiative.

Initially, two workers — the Development Worker of Nottingham MIND and the health authority's Mental Illness Unit General Manager — obtained £2,000 of NHS funding through the authority's General Manager to sponsor two conferences on Patients Councils in the following year.

Meanwhile, workers from social services and the health authority, together with the local MIND group, were busy talking to users and mental health workers about setting up Patients Councils. The idea was enthusiastically received by many users, although at this point, they were not yet confident enough to actually set the ball rolling themselves. Meanwhile, these workers formed what became, in effect, a steering group for the project.

However, an offer of funding from the Social Services Department enabled the steering group to employ a member of the Dutch Clients Union, Wouter Van Der Graaf, for three months to assist in getting the scheme off the ground.

Van Der Graaf came over for a few days in November 1985 to talk to users and workers about setting up Patients Councils. When he returned in January 1986, four volunteers had formed themselves into the project group which was to get things going. It was expected that Van Der Graaf would bring over a well tried and tested model from Holland which could simply be replicated in Nottingham without any problems, but the group were advised to start by looking not at Holland, but instead at mental health services in Nottingham and in particular at in-patient services. At first the project group tried to find out what opportunities existed which allowed users to have a say in the running of the hospital; not suprisingly there was little evidence of existing user involvement in either of the two hospitals which the project group visited.

At Saxondale Hospital (the former county asylum), there were virtually no ward meetings of any kind, although there had been meetings where people talked about the poor standard of catering. The project group also discovered that nothing had subsequently been done about these complaints. Because of this, residents stopped coming to the meetings, and because no one came to the meetings, the staff stopped them; a typical vicious circle.

At Mapperley Hospital, project group members found that a few wards were holding ‘community meetings’ when staff and residents met together, but, apparently, few issues were raised. This almost certainly had something to do with the fact that staff were present at these meetings (an issue which is discussed below).

From the discussions with users at both these hospitals, it was clear that there was considerable support for user-only meetings.

THE ESTABLISHMENT OF THE NPCSG AND THE MARCH 1986 CONFERENCE

From January to March 1986, all efforts were concentrated on setting up the first, two-day conference. Applications were strictly monitored to ensure a 50/50 balance of users and workers amongst the eighty who attended; users were heavily involved in planning the content of the conference.

The first day was spent examining the Dutch experience and some of the user initiatives which had been set up in Britain. At this stage, workers and users tended to keep themselves apart. The second day's agenda was to look at possible ways forward in Nottingham and to discuss how workers and users could co-operate in planning for the future. By now workers and users were mixing more easily and by the end of the two days, there were two main achievements: six users had come forward as volunteers to assist in furthering the project and the group had identified sympathetic workers who would support the development of the Councils.

The workers then became advisors to the group and in the summer of 1986, a group of mental health workers was set up in an advisory capacity to the NPCSG. This group, with some changes in membership, is still in existence.

April 1986 marked a transition for the project. Wouter Van Der Graaf returned to Holland and with a number of local people committed to working together, the project group was replaced by the Nottingham Patient Council Support Group (NPCSG) which was formally established with a Chair, Vice-Chair, Secretary, Treasurer and Co-ordinator. The requirement for membership was former or present experience of using mental health services and all members were asked to commit time on a voluntary basis to developing the work of the group.

Since April 1986, some non-users have become 'associate members'. They have supported the group in a number of ways including fund-raising and publicity activities, supporting members on ward visits, and conducting research. In the event of policy decisions being made, only full members can vote which ensures that it firmly remains a user-led group.

In a leaflet published in April 1986 the NPCSG set out four basic aims:

- To create more awareness and control by users of the services;
- To create user-only meetings in wards, day units and community mental health centres and support such groups in taking up issues raised by them;
- To influence the planning and management of mental health services;
- To educate workers both locally and nationally about the need for user involvement.

LOOKING BACK: 1986-1988

Looking back over the last two years, the NPCSG has made some progress towards achieving all the objectives set out above. Some forty people have been involved with the group, all of them showing tremendous determination and commitment in a wholly voluntary capacity and the group has also received heartening support from mental health workers, some of whom have at times 'put their necks on the line' to support NPCSG.

DEVELOPMENTS AT MAPPERLEY HOSPITAL

The first objective was to set up meetings at ward level and attempt to get issues resolved with staff working on the wards. The response from staff was (predictably) varied, with some being more responsive and supportive than others. Some requests, such as getting more tea and coffee, obtaining new shower curtains, and setting up more activities, have been agreed with relative ease.

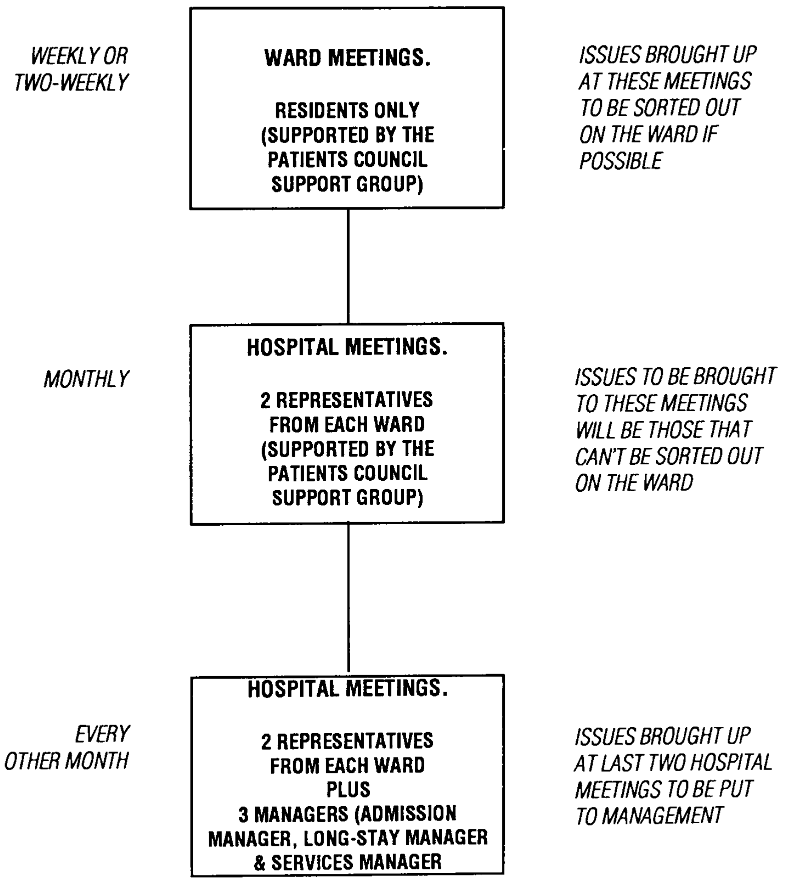
However, other issues could not be sorted out at ward level. Things like making changes in the catering system, providing better security for residents' possessions, better information for residents, improved after-care and support in the community and consultation about ward changes all needed to be dealt with by management at a higher level.

It was at this stage that the structure shown in Figure 1 was arrived at. As the diagram shows, wherever possible, issues raised at user-only meetings would be resolved at ward level. Where this was not possible, issues would be taken to a monthly hospital council meeting.

Both types of meetings would be facilitated and supported by NPCSG. The role of NPCSG in ward meetings is to encourage a meeting to be set up in the first place, to encourage residents to take part and to give advice and information on how any issues discussed can be dealt with. In some meetings, and at the request of residents, minutes are taken. However, the group has never set out to chair ward meetings but sees its role as being to support residents in running their own meetings. Recently, the group has sought information from hospital management about plans for the hospital, has passed these plans on to residents and has sought their comments on them.

Every other month, three representatives of the hospital's management would attend the (larger) monthly meeting to discuss outstanding issues and act on them. The three managers are: the Acute Services /Admissions Manager, the Continuing Care/Long-Stay Manager and the Personnel/ Services Manager.

The first of the monthly user-only meetings at Mapperley was arranged for September (1986). No one really knew what to expect, but there was considerable prior interest in the meeting. A member of NPCSG opened the meeting, explaining that this was a new venture and what the group hoped the outcome would be (namely, the establishment of a formal Patients Council). Each person was then given the chance to speak. For those present it was tremendous to witness people having the opportunity to talk about what they felt about the service they were receiving and hear them come up with useful and constructive suggestions for improving things.



THE PATIENTS COUNCIL
MAPPERLEY HOSPITAL

FIGURE 1

From the list of issues raised at this first meeting, an agenda was drawn up for the meeting with management. Initially the managers were keen to attend each monthly meeting, but it was pointed out that users needed their own time for discussion. Users generally talk more openly if staff are not present. This is no reflection on staff, but happens simply because there are barriers between providers and users. In discussing this with staff, members of NPCSG have found it useful to draw an analogy: staff who are meeting with more senior colleagues will often find it difficult to express their point of view because of the inherently unequal situation. This commitment to user-only meetings is central to the group's approach and is incorporated in its four basic aims.

For the first nine months the system of managers attending alternate meetings seemed to work. However, managers then started missing some meetings, and issues were taking too long to be dealt with as matters could only be raised with management every two months (and someone on an acute ward could well have left by the time an issue they had raised was discussed). The fact that issues were being dealt with too slowly had a knock-on effect: since it appeared that issues they raised were not being dealt with, users felt they were not being listened to and lost interest in attending meetings.

The arrangements were also not designed to cope with another difficulty. Not all wards were represented at the monthly meetings as NPCSG members could not get to every weekly (or fortnightly) ward meeting. Although wards could have meetings without NPCSG members, in practice this did not tend to happen.

MAPPERLEY STRUCTURE

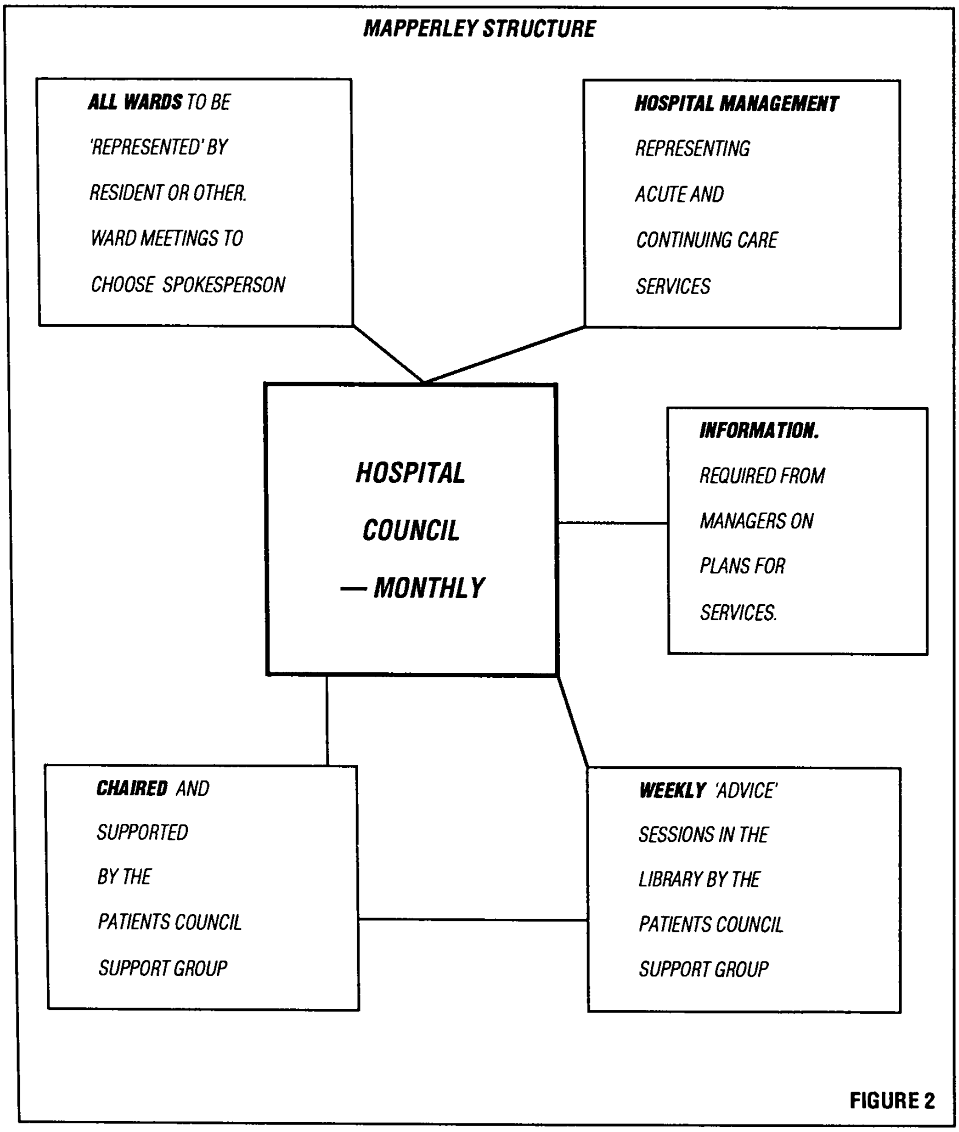


FIGURE 2

As a result, NPCSG has been looking at other methods of working, and a possible alternative structure is described in Figure 2. However, this has involved the group in a change of policy; it is proposed that each ward would send a spokesperson to the monthly meetings, but, initially at least, this would not necessarily be a service user. Certain 'rules' would need to be worked out, however, such as only allowing a member of ward staff to attend for a limited number of meetings. The ultimate aim would still be for the hospital council to be user/resident only. The NPCSG would chair and facilitate the council meetings.

Management would attend each month, with representatives from acute services and continuing care. As well as responding to issues raised by residents, they would also be responsible for feeding in to the council any future plans.

There are also plans to hold weekly advice sessions in the Library at Mapperley where residents will be able to obtain information or other forms of help in a non-threatening environment. Issues raised here could also be fed into the monthly hospital council meetings.

This new structure came into operation in September 1988 since when there have been hospital council meetings on the first Monday of each month. Issues raised so far have included: the distribution of information booklets which were produced at the request of residents; a review of catering services; discussion on the proposed closure of the hospital; and the provision of information on medication. These issues are now being tackled by the hospital council and hospital management.

DEVELOPMENTS AT QUEEN'S MEDICAL CENTRE

QMC is a large modern general hospital with a psychiatric wing comprising four acute wards and a day unit. The hospital council structure for QMC is described in Figure 3 (overleaf).

NPCSG has managed to send members to the weekly community meetings held on three of the four wards. At the weekly ward meetings the NPCSG informs people of the group's activities and invites people to attend the weekly user/resident-only meetings which is held each Thursday morning away from the wards. Issues raised at these weekly 'off-ward' meetings are fed back to the ward staff, or to the Clinical Nurse Manager as appropriate.

The fourth ward is mainly for elderly people and NPCSG's role here has been slightly different. Residents on this ward are less enthusiastic about trying to make changes to the system and have shown more interest in having social activities on the ward. They have wanted to involve NPCSG members more on a 'sit and chat' basis.

The day unit also has its own weekly user-only meetings and issues from there are fed back to the 'off-ward' meetings described above.

A number of different issues have been raised including problems with catering, lack of information for users and inadequate daytime activities.

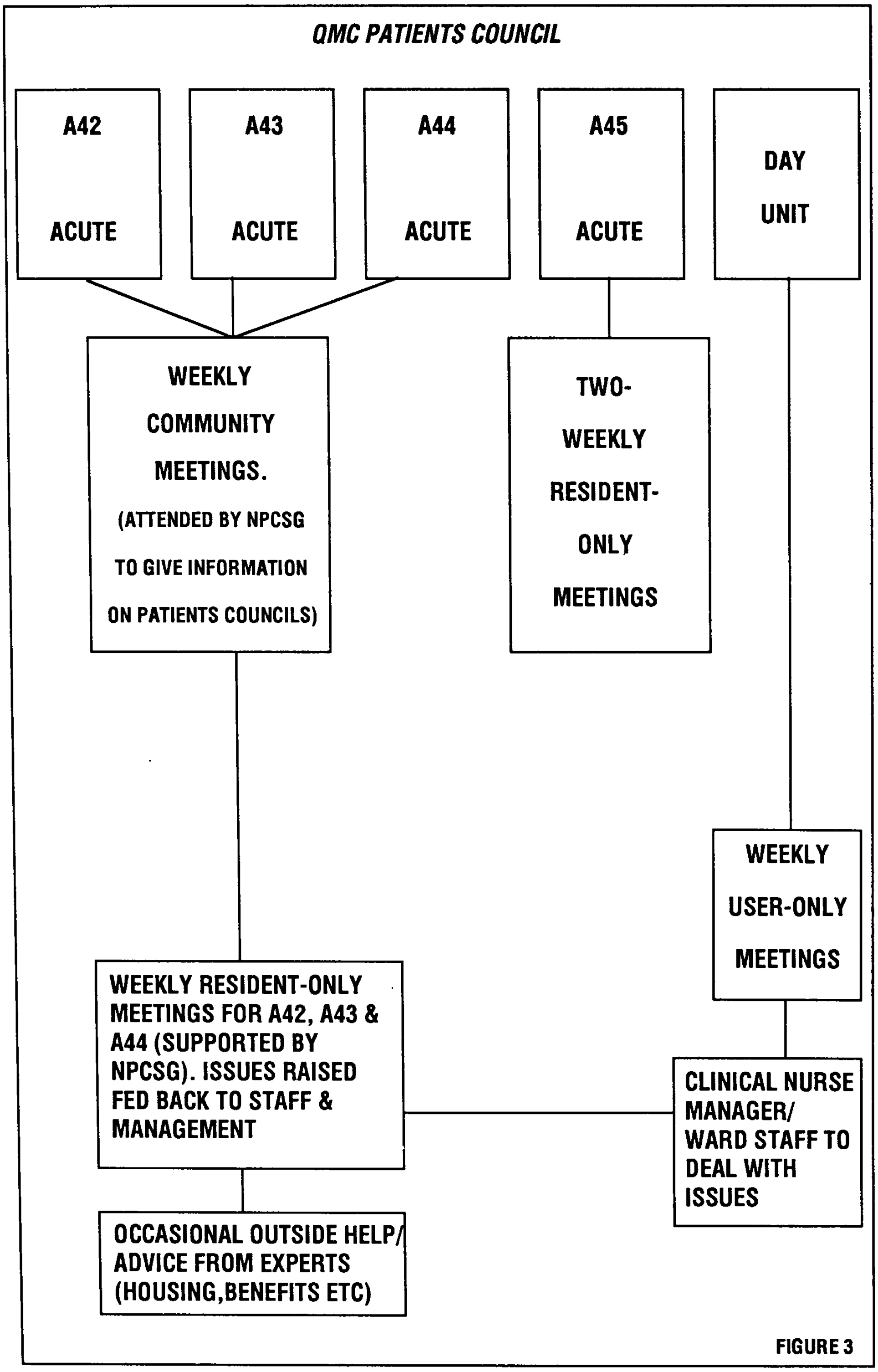


FIGURE 3

Problems with catering arose because of the hospital's delivery system. Basically there were three 'blocks' of catering deliveries and the psychiatric unit was in the last block. Invariably food was turning up late and was disrupting life on the wards as a result. Equally importantly, because meals were delivered late, the food was often not hot and not up to standard. Ward staff and the consultant had attempted to get changes made without success. At one of the Thursday meetings residents asked the group to write to the catering manager on their behalf, requesting a meeting, and this was done. To his credit, the manager listened to the complaints and undertook to make changes. As a result, the food is now delivered in the middle block, and the food arrives in good time and in good condition. In addition, a hospital catering review has been instigated which should result in a better service for everyone concerned. Meanwhile, the Community Health Council is monitoring the situation.

Another problem which has been tackled is the lack of information available to people on admission, during their stay, and when they are about to be discharged. People did not always understand job roles and titles or the abbreviations used. What is an OT or a CPN? What does a social worker do? Faced with leaving hospital people wanted to know how they could get help and support in the community. What did community psychiatric nurses offer? What did the local MIND group do? Is there a group for manic depressives? Making more and better information available has been one of the group's successes — people are now getting more written and verbal help with their queries. Hopefully this has a knock-on effect of making the public better informed too. If everyone becomes more aware of what sort of services are available and how people are helped, maybe some of the fear and stigma will go away.

Despite some successes in these and other areas, the group still has its ups and downs. Attendance at weekly meetings tends to be erratic, although some have been remarkably well attended, for example where a speaker was invited to come and explain the new social security regulations. At other times no one turns up. But members of NPCSG are there each week for people to use should they need help.

COUNCILS IN THE COMMUNITY

Initially NPCSG put all its efforts into developing its work in hospitals. More recently, though, the group has started to become involved in work in the community. Nottingham is divided into seven 'sectors' or areas (see Figure 4 overleaf), each sector having a multi-disciplinary mental health team operating from a base which acts as office, clinic and sometimes as a centre for groupwork (eg. a women's group) or treatments (eg. stress management). Each sector has an acute admissions ward at either QMC or Mapperley.

As a result of NPCSG's work in the hospitals, some sector team workers sought the group's help in trying to find out what past and present users thought of the services. By mid-1988, the group had had some involvement with all sectors although the outcomes of each have been somewhat different.

NOTTINGHAM MENTAL HEALTH SERVICES

IN SEVEN MONTHS

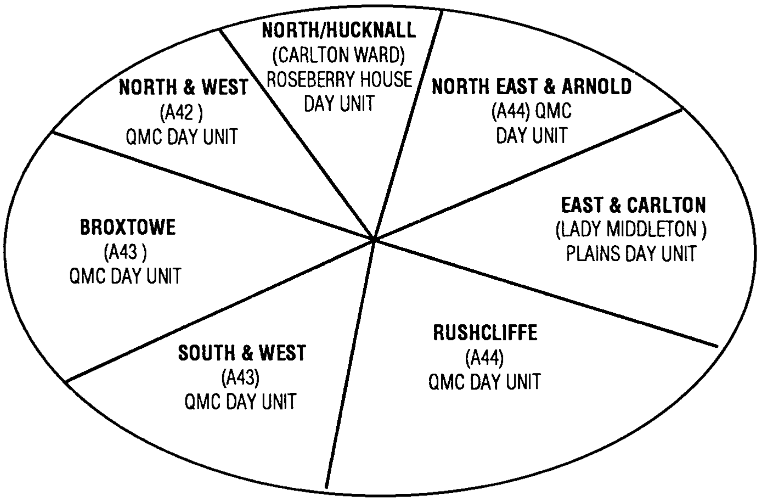


FIGURE 4

The group invited users in the South and West sector to attend discussion forums which were well attended and resulted in the establishment of a user group which, for a time, was reasonably successful. However, the rather mixed nature of the sector — including districts with large ethnic minority populations, high unemployment and poor living standards, and a white, largely middle-class area and a large modern housing estate — resulted in very diverse user expectations of the discussions. It was hard to find a common agenda when in some parts of the sector people were requesting more social/support groups, whilst for others the main issue was services more appropriate to particular ethnic needs. Because some members were more interested in campaigning than in developing social activities, some people lost interest.

The group had other problems. There were difficulties in finding a suitable meeting place. The sector team was based in the city centre which wasn't a popular venue for some people but on the other hand, it proved impossible to find a central point within the sector. The fortnightly meetings were also too frequent for some people and after a spell of reasonably successful meetings, attendances fell away and the group folded. However, on the initiative of a local NPCSG member, a group has now been restarted which, hopefully, will learn from earlier mistakes.

Initiatives in the North and Hucknall sector have been more successful. The Roseberry House Group has been meeting monthly since the summer of 1986, and has developed a range of activities. A social services grant means members' travel expenses are paid, which has made a considerable difference to those who are unemployed or on low incomes. Social activities have become an important element. The group has also become a support point for people leaving hospital since regular meetings on the sector's ward mean people get to know of the group before they are discharged. This group has also been able to make some impact on sector planning as workers are regularly asked to attend meetings to seek users' views. This has also been a two-way process as on the occasion when a community psychiatric nurse who came to hear people's views also discovered that many users were unaware of the existence of CPNs (and had no idea of what they did either).

This group has also been involved in commenting on new services. When a new day unit was proposed, the group put forward its ideas about how the new unit could offer an appropriate and accessible service, based on members' experiences of existing services. Many of the points they put forward (about referrals, choice of treatments, and user involvement etc.) were included in the plans for the unit. A member of the Roseberry House Group is involved with the commissioning group and ensures that the user's perspective is always to the fore. Members of the Group have also been involved in the appointments of staff nurses and the sister for the Day Unit, and have been consulted on proposed housing developments in the area. More recently, two people were involved in talking to the candidates for the new consultant's appointment.

In the East and Carlton sector, the NPCSG sought the views of local users about the setting up of a day/drop-in centre. The Dale Centre opened in 1987, and is virtually user-run, those attending being responsible for decisions on meals, activities and other matters.

The Rushcliffe sector has also now approached NPCSG asking for help in setting up a user group and users are already involved in the planning of a new day 'resource'. (The term 'resource' rather than 'day centre' is a deliberate choice of words — users were looking for a real alternative to the traditional 'day centre' model where user involvement and consultation have never played a major role.)

The NPCSG has done some work with the Broxtowe sector team on their plans for a new mental health centre. After talking with a team member, it was felt that one way of involving users could be to circulate a questionnaire before the detailed planning stage. The views expressed in replies to the questionnaire could then be incorporated in the planning process. It is hoped that the centre will be in operation soon.

The remaining sectors have expressed a willingness to involve users in planning services and NPCSG hopes to work with them in the future.

THE FUTURE OF PATIENTS COUNCILS IN NOTTINGHAM

Ideally, NPCSG would like to see a Patients Council in each hospital with representatives from every ward, and contributing significantly to service planning and delivery. In the community the aim is for each sector to have a recognised user-group meeting regularly and commenting on plans for future services as well as on existing provision. If individual Councils are established in each sector, NPCSG would hope to bring them together into a city-wide Council, able to comment on the overall health authority's strategy for mental health services.

NPCSG currently has some input into recognised bodies. A Group member is on the Community Health Council and regular meetings of user groups with the CHC are planned. NPCSG is also represented on the City Council's Working Party for Disabilities, on the Joint Care Planning Team (Mental Health), the Nottingham Advocacy Group Management Committee and the Executive Committee of Nottingham MIND.

The greatest problem for NPCSG is the lack of a full-time worker. At present the Group relies on the commitment of volunteers (some of whom get full-time jobs or move on) and the involvement of MIND's Volunteer Co-ordinator and Development Worker.

The NPCSG has twice applied for Inner City Area funding and after a first unsuccessful attempt the Group is waiting to hear whether the second application has been more successful. At the time of writing (February 1989), the second application has been referred to the Joint Care Planning Team for consideration and it seems likely that funding will be made available for the appointment of a Patients Council support and development worker. However, with a growing number of self-advocacy or advocacy groups springing up around the country a proper system of funding is urgently needed. (In Holland the Dutch government has officially recognised this need: psychiatric hospitals are obliged to contribute to a national fund which then independently funds advocacy schemes). Securing funding which is (reasonably) independent and does not place constraints on the activities of advocacy groups is not easy but proper resourcing is essential if the movement is to survive and grow.

To summarise the work done in Nottingham is difficult. If one looks at success in terms of actual changes that have come about because of the group's intervention then maybe it doesn't look too great. But the fact that the NPCSG is still around after two years is a major achievement; in the early days many people thought it would be a five-day wonder. They've been proved wrong.

Overall, the major success has been in changing the attitudes of mental health workers who are now more ready to consult users before services are developed. Increasingly, users are being involved in projects as a matter of course, rather than as something innovative or as an afterthought.

Developments in Nottingham have been mirrored elsewhere and user groups are being involved in many more mental health forums. It is becoming rare for national conferences not to involve user groups, and health and social services training programmes are increasingly involving users.

Compared with user movements in other parts of the world, Nottingham and, indeed, Britain are still in their infancy but the scene is set for rapid growth over the next few years. People who use services have a unique experience of those services and their contribution is essential if we are to provide a better and more appropriate service. To quote Hans Weight of the Dutch Patients Council Foundation: "We have started a movement, a movement that can't and won't be stopped".

Breaking new ground — The Lambeth Community Care Centre
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