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OBTAINING

SHIRLEY McIVER

OBTAINING THE VIEWS OF USERS OF MENTAL HEALTH SERVICES

Shirley McIver

Consumer Feedback Resource

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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.

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PREFACE

This publication is the third in a series aimed at helping health service staff to obtain the views of service users, and it is written for anyone who has been given this responsibility, whether nursing, medical, paramedical or managerial. The series presumes no social science background and offers a flexible approach which is very amenable to local adaptation and interpretation.

The example questions and response formats given here are for guidance only and can be altered for individual use. Information about non-survey methods is provided and the reader is encouraged to combine a number of methods to achieve useful information in different circumstances and with different types of service user.

The book is produced by the Consumer Feedback Resource, an information and advice service aimed at improving feedback techniques, disseminating information about current projects and examples of good practice, networking, and building up a source of data about patient views and experiences.

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1 INTRODUCTION

Health care providers face increasing pressure to obtain the views of service users in order to monitor and improve service quality. The last few years have seen a stream of publications, most notably the Griffiths Report in 1983 and the Government White Paper *Working for Patients* in 1989, which advocate the use of surveys to check that services are meeting the requirements of patients.

Although most health care professionals now accept the desirability of obtaining user views, many remain uncertain about the best way of doing so. In particular, there is concern that there may be some users who are unable to provide useful or valid opinions about services received. These include people with learning difficulties, children, elderly demented patients and those suffering from mental distress.

It seems ethically desirable to assume that, along with other rights, every citizen has the right to give their views about a particular service. However, in order to obtain valid and useful information, it is important to choose the right method. The self-completion questionnaire survey, though popular, does not work in all circumstances. This book sets out to examine the question of how to get the views of those suffering from mental distress, including elderly demented patients, by looking at previous and current work in the area (see Whittaker, Gardner and Kershaw, 1991, for people with learning difficulties). Different approaches are assessed and the methodological issues are discussed.

There is no single, recommended or standard method for obtaining user views in any service area because not only is the practice of incorporating user views into the assessement and monitoring of service quality in the early stages, but also the best approach to adopt will depend upon the type of user involved and the aim of the exercise. This book describes a range of approaches, providing examples of relevant questions to ask users where this is know, but leaving the final choice of question mix and approach to those concerned with the process of obtaining the views of users of mental health services.

A useful place to begin is with an early pioneering approach to the subject – appropriately enough by the King's Fund Centre. In 1972, Winifred Raphael tried to: 'devise a method by which psychiatric hospitals could themselves discover the views of their patients' (Raphael, 1972, p7). Since little work had been done on attitude surveys with psychiatric patients, Raphael tried out three methods in wards similar to each other in each of three hospitals. These methods were: individual interviews; a complex questionnaire; and a simple questionnaire.

An anonymously answered simple, self completion questionnaire was found by Raphael to be satisfactory, except for use on psycho-geriatric wards. The questionnaire was then tried out by another six large psychiatric hospitals and the results from 2,148 patients were analysed. About two-thirds of the patients participated, out of the wards included in the survey, and Raphael commented that of these 'only 2 per cent gave answers that were irrational.'

Copies of Raphael's report and questionnaire for patients in psychiatric hospitals and another she devised for patients in psychiatric wards in general hospitals, have been regularly requested since the 1970s, although no record has been kept of how often these have been used. There have been many changes in British society in general and the NHS in particular since the 1970s, so it is worth investigating the area with a view to assessing the status of Raphael's questionnaire. Is her pioneering work still relevant in today's changed climate?

The rise of the patient advocacy movement is one development which has direct implications for mental health services. Patient advocacy developed first in America and Holland during the 1970s. In Holland, where psychiatric services are provided in private hospitals, the movement has involved the development of ward based patients' councils. These councils have been supported by managers who want to communicate with patients in order to improve service quality and also by the government, where members see the movement as an aid in the process of standardising psychiatric hospitals. Legislation has been drawn up which states that each Dutch psychiatric hospital must have a patients' council (see Barker and Peck, 1987 and Wiegant, 1988, for further details).

In the USA, the movement has developed in opposition to the Government rather than with institutional support as in Holland. It developed out of the separatist organisations of the 1960s and the anti-psychiatry movement in particular. Mental patients' liberation fronts and similar organisations made their initial appearance with denunciations of mental hospital abuses, but soon many developed informal self help drop-in centres which attracted patients away from formal conventional psychiatric programmes. The USA now has many aftercare and support services which are run by users and ex-users on distinctive alternative lines but receive public funding (see Patmore, 1988, and Brown, 1981 for further details).

In Britain the patient advocacy movement is developing among a number of different types of service users, including people with learning difficulties (see Whittaker 1990) and the elderly (Age Concern, 1989) as well as those suffering mental distress. In addition it is developing in a number of different ways. Garry Robson (1987) has described these as follows:

★ **Lay or citizens advocacy** – where skilled volunteers supported by an independent agency work with individuals on a long-term basis.

★ **Paid advocacy** – where skilled workers are paid by an independent agency to represent the interests of individuals, usually in the short-term.

★ **Self-advocacy** – where, singularly or collectively, individuals work on their own behalf to realise their own interests.

Within mental health services, development is mainly by means of the self-advocacy model, taking the form of patients councils and mental health forums. Examples of these will be given in later chapters and further details of patient advocacy organisations within the mental health field can be found under Useful Addresses. The relationship between advocacy organisations and obtaining the views of users of mental health services will be discussed in Chapter 2.

In addition to the rise of the patient advocacy movement, there have also been changes in governmental policy concerning mental health services. In particular, there has been a move towards providing care in the community rather than in long-stay psychiatric hospitals, but as yet there appears to have been few attempts to elicit user views on different aspects of community care. Guidelines based upon user views do exist, however, (eg Beeforth *et al*, 1990; and *Good Practices in Mental Health*, 1989, for primary care) and so it is quite possible to identify key issues which are of concern to service users and thus to elicit views on local services.

Finally, there is the question of different categories of mental health service user. There are likely to be significant differences between elderly demented patients, young and adolescent patients, and black and minority patients, and these differences will affect the way their views are elicited, as well as the issues that are considered important by them.

It is clear that there are a number of different aspects to the process of eliciting mental health service users' views which require examination and these will be tackled in the following chapters. Firstly, though, the methodological issue requires more consideration and this vital aspect will be examined in the next chapter.

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2 METHODOLOGICAL CONSIDERATIONS

The aim of all user feedback work is to elicit information which is both accurate and useful. Briefly, this entails collecting information which reflects the views, experiences or opinions of service users and which relates to issues considered important by service providers, collected in a way which enables staff to make changes to improve service quality (see McIver 1991, A, for further details).

In order to collect *accurate* information about users' views, a number of conceptual and methodological issues have to be resolved. These include:

- ★ obtaining a representative sample of users
- ★ asking the right questions
- ★ asking questions in an appropriate manner
- ★ understanding and interpreting the data correctly.

Where users of mental health services are concerned,there are a number of factors which make these issues particularly problematic.

A Representative Sample

This can be difficult to achieve for three main reasons. Firstly, some users may be too sick to answer questions. This can be the case with users of other services too, but fear, hostility and vulnerability may make users less likely to respond, particularly while still under treatment.

Secondly, even when treatment has finished, for some patients there may be feelings of acrimony, conflict and emotional distress associated with the circumstances of treatment and the treatment received, making users less likely to want to respond. This can be particularly the case where black and minority users are concerned.

Thirdly, if providers wait until after discharge before contacting users, they may find it difficult to reach a large number of people because of their itinerant lifestyle.

The Right Questions

These are questions which focus upon the service users' agenda of importance, as well as that of the service provider. They are also questions which produce information which facilitates improvements in service quality.

Many questionnaires currently used by health service providers are weak in this respect. Frequently questions are adapted from other questionnaires with no thought given to the origin of the questions – often they have been drawn up by staff without any prior consultation with service users.

In addition, questions frequently ask about satisfaction with services; that is, they ask patient to make judgements about various aspects of a service. This assumes that patients possess sufficient knowledge of services to compare them with an expected standard, yet patients are rarely informed about service standards or given enough information to know what to expect from a service.

General questions about satisfaction – such as 'on the whole were you satisfied with the service you received?'– followed by a choice of options from very satisfied to very unsatisfied, are of little use because they do not inform the service provider about *which aspects* of a service are good or less good. The user is forced to make a generalisation, preventing an evaluation (which involves comparison) under the pretence of asking for one – a frustrating exercise for all concerned!

Users of mental health services are in a particularly vulnerable position because, more than other patients (apart from people with learning difficulties), they are not expected to know what is good for them. Beliefs about the nature of mental illness encourage service providers to discount the views and opinions of patients as part of their illness.

Asking in an Appropriate Manner

Probably everyone knows that questions must be asked in an unambiguous manner; that they must be clear and raise only one point at a time, and that they must not lead the respondent to reply in a particular way. It is doubtful whether everyone knows that the self-completion questionnaire format is not appropriate for every service user. This format or 'instrument' is so widespread that it is usually the automatic choice for a prospective survey.

It is only appropriate to ask questions using the self-completion questionnaire if all of the potential respondents can see, read English (or the language written), use their hands, and can understand and feel comfortable with this particular format which is formal and highly stylised. This will not be the case with all types of mental health service user. Elderly people suffering from dementia, many black and minority users, some of those suffering from alcoholism and drug misuse, and those prescribed drugs which affect their eyesight and concentration, for example, will not be able to fill in a questionnaire themselves.

When Winifred Raphael of the King's Fund Centre investigated the views of patients in psychiatric hospitals in the 1970s, she found that between 85per cent and 52per cent of patients in the different hospitals surveyed were able to complete questionnaires. She writes that the percentage:

> *'...depended on the proportion of long-stay wards with elderly patients, some of whom were senile, and on the interest promoted among the ward staff and the patients. It was impossible for some of the patients to participate because they could not see to write, did not speak English or were too ill. Others were apathetic about joining in and were not pressed to do so, and others, mainly elderly people, tried but found the questionnaire baffling and returned blank forms.'* (Raphael 1972, p10)

Self-completion questionnaires are also only useful when the aim of the exercise is to monitor service standards or check on a set of issues that are known to be important. This method is not useful for the exploration or investigation of issues; that is, for finding out the critical concerns of patients or why they are not satisfied, or for asking patients what they consider can be done to improve service quality. Exploration requires a method which will collect qualitative (narrative) data rather than quantitative (numbers or frequency). Examples of these methods include the unstructured or semi-structured interview and the focused group discussion, or informal or 'quasi' methods such as patient advocates, liaison officers, and advisory groups (see McIver, 1991, A, for further details).

Understanding and Interpreting Data

The analysis of data from questionnaire surveys appears to be straight forward because it is just a case of aggregating the scores – that is, counting the numbers of people who tick a 'yes' or 'very satisfactory' box in answer to a question and then repeating the process for the other responses.

The fact that the procedure is simple does not mean that anyone can carry it out. Expertise will be needed to make inferences from the statistics. The fact that 60 per cent of people ticked the 'yes' box in answer to a question needs interpretation by someone who can relate the scores to any obtained in similar exercises carried out previously, either by the same organisation or elsewhere. Furthermore, he or she must understand the limitations of the question being asked, and those of the sample of respondents. He or she must have a good knowledge of the aim of the exercise and what will be important to those whose job it is to read the final report and act on the recommendations.

Where users of mental health services are concerned, this means that the person who analyses the data must be aware of the problems mentioned above – those of representativeness, vulnerability, the limited nature of self-completion questionnaires, etc; they should also be able to draw out the relevant details for the intended audience of the report. A list of statistics is very difficult and time consuming to make sense of.

The analysis of qualitative data from interviews and group discussions is more time consuming but easier to interpret because the meaning is given by the speaker and does not have to be interpreted to the same extent as that from a fixed response to a question. It is more difficult to make generalisations from qualitative data, though, because usually fewer respondents are involved (see McIver, 1991 A, for further details).

Overcoming the Problems

The list of problems described may appear daunting to those who wish to investigate the views of mental health service users, but these problems can be overcome to a large extent. It *is* possible to get accurate and useful information.

Firstly, it is important to establish the service users' agenda of importance. This is usually achieved using qualitative research methods, such as interviews and group discussions. Patients' advocates, patients' councils and patients' forums can also help identify issues of major concern to users. As these are not formal social science methods they are not specifically aimed at collecting user views and health care staff will have to recognise that those involved may have their own agenda – providing staff with information about what service users consider important areas of service quality may not be top of their list. Nevertheless taking steps to facilitate the improvement of service quality from a user perspective should be very important to them and so patients' groups can be very useful developments as far as staff are concerned.

Secondly, it is vital that the views of a representative sample of users are gathered. This will probably mean that more than one method will have to be used and also that some users will need preparation before they can take part. The likelihood is that a self-completion questionnaire will have to be teamed with interviews and patient advocacy. Particular combinations of methods will be examined under the different service sections but the following combination is a general guide:

- ★ Patient advocacy will help those patients who are unwilling or unable to express their views to have a voice, either by facilitating self-advocacy or by speaking on their behalf.
- ★ Interviews will elicit the views of those who want to respond but cannot read or write or who feel unhappy

about forms. Interviewers may also be successful in locating those who live an unsettled lifestyle. Letters addressed to hostels may be ignored but an interviewer might be made more welcome.

★ Self-completion questionnaires will elicit the views of those remaining but this number will vary from ward to ward and in different service areas.

Thirdly, every effort should be made to reassure users of mental health services that the information they give will be confidential and anonymous and will not be used against them in any way. This will have to be tackled in a number of different ways also; patient advocacy, the use of independent interviewers, sealable envelopes for questionnaires, collection boxes rather than staff collection of questionnaires, an introductory letter from the 'customer service' or 'quality improvement' department rather than hospital or ward management, etc.

Fourthly, care should be taken only to ask patients for judgements or evaluations of services if they have enough knowledge, experience and information to be able to make an evaluation. Judgements rely on expectations and many people may have low expectations (elderly people who can remember a time without the NHS, for example). Does this mean that services should match these low expectations or should they strive for excellence?

If patients are going to be asked to make judgements, then the standards aimed at should be made clear to them and very specific questions aimed at monitoring these standards should be asked. This is not the only option however. Patients can also be asked to supply information about what happened to them, i.e. about their experience of service delivery, and staff will then be able to judge whether these experiences show an acceptable standard of service delivery or not.

Both types of questions can be structured – limited response – and produce statistical information. For example, it is possible to ask a patient about privacy in the following ways:

1 How do you rate the level of privacy given during your stay in hospital?

Very highly

Highly

Fair

Low

Very low

2 Were you satisfied with the level of privacy given during your stay in hospital?

Yes

No

Comments

These two examples require patients to make a judgement, so patients must first be provided with a list of standards which illustrate the level of privacy aimed at by the hospital, that is, a charter or service agreement which details what constitutes a high standard of privacy at the hospital. This might include:

a) all beds will be separated by partitions of such and such a height or, all patients will have a choice of bed in a single room;

b) all lavatory doors will have locks;

c) all washbasins will be screened individually;

d) all patients will have access to a telephone which is sound-proofed;

e) all patients will have access to a room or area where they can talk to their visitors without being overheard.

Either these details will have to be included above the question on the questionnaire, or in a separate information sheet which is given out at the same time. If they are made available earlier, it is difficult to be sure that patients have read and remembered the information.

A more simple and straight forward approach is to ask questions which aim to collect details relating to the service standards. A standard relating to privacy may then be measured using a number of indicators, some of which it will be possible for staff to examine using a checklist, and some which will depend upon reports of patient experiences. For example, environmental indicators, such as locks on lavatory doors and partitioning, can be checked by staff. Information about working practices and ambiance are best elicited from patients themselves because rules are not always put into practice. For example, privacy may be checked by asking patients questions such as:

1 Were/are you always able to speak to your visitors in a place where you could/cannot be overheard?

Yes

No

Comments:

2 Did/do you feel that you have/had a personal bedroom?

Yes

No

Comments:

3 Did/do you have a locker with a key where your belongings were/are safe?

Yes

No

Comments:

The Yes/No/Comments format is used here for preference because it is simple, yet allows patients to elaborate or explain if they wish. Some researchers consider that the Yes/No format can encourage a response bias but Winifred Raphael found no evidence of response bias when she experimented with this format in the 1970s. Raphael constructed an alternative questionnaire covering the same topics but with half of the questions rephrased so that half of the favourable answers would be 'no'. She compared the responses to this questionnaire with the responses to the other questionnaire and interviews covering the same topics. She writes:

> *'The answers to the second questionnaire showed no closer correlation with the rank order of answers from the interview than did the first questionnaire; it was answered by a smaller proportion of patients and was more difficult to analyse.'* (Raphael, 1972, p9)

The yes/no/comments (or explanations/suggestions) format is the one used in all of Raphael's questionnaires which have been used frequently since the 1970s. It has also been used recently in outpatient questionnaires piloted by Trent Regional Health Authority, with an additional 'Does not apply' option where necessary (McIver 1991,B).

Raphael also often included two open questions at the end of her questionnaire. These were phrased:

> What did/do you like best about .... (the hospital service, etc.)
>
> What did/do you like least about .... (the hospital service, etc.)

These two questions will pick up any important items not covered by the questionnaire and may well pick up new items as changes occur.

Fifthly, questionnaires do not encourage the creation of a dialogue between service users and staff. The method is a one-way process in which user views are collected and no information about the results of the survey or any changes made, is fed back to them. This can perpetuate the often already existing technical approach which treats users as 'objects' (in this case of research) rather than as people. The method does not involve users in exploring issues, seeking solutions to problems, or making decisions about service provision, processes which treat them as human beings.

This limitation can be overcome to some extent by ensuring that service users (and staff) are informed about results, recommendations and possible future action. This can be accomplished in many ways, from short, easy to read, and interestingly presented details about the surveys displayed on notice boards in areas where service users wait, through press and radio reports, to public meetings and displays at local fairs and similar events.

The best way to overcome the limitation, though, is to use methods which encourage more participation. These can be in addition to surveys and can be part of a wider initiative to improve dialogue between patients and staff, to increase staff understanding of the patient's perspective, and to explore problem areas and issues important to the patients. Discussion groups, advisory forums and patients' councils are all suitable and can help service providers to think issues through and develop solutions to problems.

In sum, self-completion questionnaires can be used with some users of mental health services but it is advisable to use other methods to get user views as well. This is to make sure that the views of those who cannot or will not fill in questionnaires are obtained, to explore issues, and to encourage dialogue between patients and staff.

The way questions within a questionnaire are constructed is crucial, as is layout, and only general guidelines have been given here. A more detailed examination of questions which are specific to particular types of mental health service will be undertaken in the following chapters, but more general advice on questionnaire construction can be found in Dixon & Carr-Hill, 1989; Luck, Lawrence, Pocock and Reilly, 1988; on methods in general, McIver 1991A; and on qualitative methods, such as interviews and discussion groups, Walker, 1987. Further information on informal group methods can be found in Winn (ed) 1990; and on patient advocacy and starting patients councils, from Nottingham Patients Council Support Group, Labourn Street, Nottingham NG3 1BQ.

Lastly, some comments need to be made about the second part of the aim to collect information from users which is both accurate and useful. The collection of *useful* information is not just about getting the questions right, although this is certainly important. Information is useful if it is fed into a system which is geared towards improving service quality from the user perspective, that is, there must be a willingness among all staff to change from an organisation which historically 'knows best' what its users need, to one in which users can participate in decisions about their care.

Whether the feedback from users will be useful or not is directly connected to the issue of organisational change; that is, the development of a customer service oriented culture. This can be particularly difficult where mental health services are concerned because of a prevailing view that patients suffering from mental distress are unable to know what is best for them because their illness affects their reason. Those whose behaviour is socially unacceptable seem to lose the right to have a point of view which means anything – their views are not respected. It is also assumed that they will not understand why events are happening in the order in which they are so that explanations about what will happen next are not given (GMPH, 1988, Beeforth *et al*, 1990).

A customer service oriented culture, or a patient oriented culture, is one which is responsive to the patient or user as a 'whole' person (Harris, 1978). It involves staff training which aims to change the attitudes, knowledge and behaviour of staff. Information collected from service users can become part of this training process, thus improving the usefulness of the information.

In conclusion, the key to planning a programme of user feedback is to think *diversity:* adopt a many faceted approach which aims to treat users as people and involve them in dialogue. This approach is being adopted by a growing number of health care providers.

For example, one locality in the Mental Health Unit at East Surrey Health Authority is in the process of implementing the following steps:

1. A user group comprising past and present users.
2. Staff development and awareness training across the range of health care, social services and voluntary groups involved.
3. Customer sampling approaches, which include a suggestion box, patient satisfaction questionnaire, sample exit interview, open forum meetings and a support group for carers and relatives which is encouraged to comment on the efficacy of services.
4. The formation of a Quality Assurance Group comprising mental health team members, representatives from the wider local community, representatives from appropriate local and national voluntary organisations together with users of the service and their carers or relatives. This group is charged with developing service standards, establishing a programme for monitoring these standards and a system for evaluating the service.
5. Information gained through these processes will be collated and made available to the planning and policy team so that

future decisions on service provision and the redeployment of resources can be made in the light of accurate local information. Representatives of users of the service and their carers will be asked to join the planning and policy team and to take back information from the planning meetings to the user groups (Davies, 1991).

No doubt cost will be one of the factors influencing choice of method and it stands to reason that more cost will be involved in using a variety of methods such as that described above, than in one method alone. However, it is important to take the following into consideration:

1. Some approaches, such as suggestion boxes and inviting users onto groups, such as the Quality Assurance Group and Planning and Policy team, cost very little and yet the potential long-term gain is high.
2. Qualitative methods (such as interviews and group discussions) are labour intensive and therefore costly. As the aim is to get an idea of the complexity and range of views rather than the views of a representative sample as in a quantitative survey, far fewer users can be involved, so bringing the cost down.
3. Patients' councils and similar informal methods will probably cost less to run over a year than a large questionnaire survey. This is because users volunteer their time to discuss issues and the only cost is providing administrative support such as a meeting room and a facilitator to help start the council and monitor progress.
4. Self-completion questionnaire surveys appear to be cheap to run, particularly if questionnaires are copied from elsewhere, photocopied and handed out by staff, but this practice is a false economy because it is likely to produce poor quality information which cannot be used. A well designed and well distributed questionnaire is going to cost money at the crucial stages of design and production, and ensuring a representative sample of repondents, but

this will be money well spent if the aim is to monitor user views at regular intervals. Some of the initial cost can be offset by the number of times the questionnaire can be used in the future. Again, short-term cost will lead to long-term gains.

In sum, the initial short-term costs of setting up a variety of user feedback projects should be set against the potential long-term gains of this approach. One-off projects may cost less initially but over time the expense of an uncoordinated short-term aim approach is greater because the information gained is piecemeal rather than incremental.

A number of basic methodological issues have been discussed, laying the ground for feedback work, but specific issues relating to different aspects of mental health services need also to be examined before the views of users can be collected effectively. This examination will take place in the following chapters.

3 INPATIENT CARE

Winifred Raphael's *Psychiatric Hospitals Viewed by their Patients* published first in 1972 followed by a revised edition in 1977, forms a milestone in the short history of getting the views of psychiatric inpatients. In a tone of apparent ironic astonishment, a reviewer in *The Economist* at the time of the first edition wrote:

> '*...The King's Fund has pioneered a method of finding out how these hospitals are seen by patients – real patients – actually in them.*' (Raphael, 1977, back cover)

The questionnaire Raphael devised has been used frequently but is it appropriate for the 1990s? Does it cover the relevant issues in the right way?

The Raphael questionnaire is for self-completion. It consists of 19 questions covering four main areas: meals and clothes; the ward environment; treatment; work and social activities. Each question is followed by the option of a yes or no answer with room for 'explanations and suggestions'. These are followed by a further question, No.20, which reads:

> '*Do you like your stay here, apart from being away from home?*
>
> *Very much In most ways Only fairly well No*'

Finally, there are two questions asking patients what they like best and least about the hospital.

The structure of the questionnaire for psychiatric patients is very similar to that used in other patient surveys carried out by Raphael during the 1970s and has similar strengths and weaknesses. These have been examined in an earlier publication dealing with outpatients (McIver, 1991 B). The strengths of the Raphael questionnaire can be summarised as follows:

Strengths

- ★ It is well laid out, making it easy for service users to complete.
- ★ Most of the questions have simple yes/no answers which facilitate analysis.
- ★ There is space for comments, and those answering 'no' to a particular question are encouraged to add explanations and suggestions, allowing users to go into more detail if they so wish. This provides valuable information about the kind of improvements which users want.
- ★ It covers a number of different aspects of the psychiatric inpatient service, making it possible for managers to obtain views on different aspects in one survey.

Although the weaknesses of the Raphael questionnaire have also been discussed in the earlier publication, the precise way in which these weaknesses can be overcome in the psychiatric inpatient context has not been covered and so needs to be examined in detail.

Weaknesses and how to Overcome them

1. Agenda Setting

The questions appear to have been set by service providers rather than users. Raphael does not mention having carried out any exploratory work to find out which subject areas and issues were considered by users to be important. Given that only a few questions are asked, each question becomes extremely important and the number of questions devoted to each topic should reflect its level of priority to the patient. This suggests that ward environment (8 questions) is the most important aspect. More recent research and comments given in response to the last two open-ended questions on Raphael's questionnaire indicate that this is not the case. Raphael herself remarks:

> *'Over two thirds of the topics raised spontaneously, both among those liked best and those liked least, depended on human rather than on physical factors.'* (Raphael, 1977, p.7)

This is not to say that physical factors such as colour of walls, absence of pictures, arrangement of beds, absence of lockers, etc. are unimportant, but that other factors which are not covered in much depth in the Raphael questionnaire may be equally important.

In order to overcome this limitation, questionnaires should also include questions which are more closely related to issues which service users feel are important. These issues can be discovered by means of qualitative methods such as unstructured or semi structured interviews, by using critical incident technique, holding discussion groups, or by the use of patient advocates or patients' councils. These methods have already been referred to and are described in detail in McIver, (1991 A).

Having highlighted the need for prior exploratory work on user views, it is worth pointing out that much work of this kind has already been carried out in many service areas. As far as psychiatric inpatients are concerned there is one important study which has produced details of the issues which users consider important.

Camden Consortium, a group of service users and others concerned with mental health in Camden, in conjunction with Good Practices in Mental Health (GPMH), produced *Treated Well?: A code of practice for psychiatric hospitals*, in 1988. In the Introduction it is described as: '...an attempt to listen to what people have to say about their experiences of being in hospital.' (p.5)

The information from patients is reported under six headings, further divided into subheadings, and appropriate good practice statements are collected into a checklist at the end. The material can be summarised as follows:

Hospital Admission

Patients expressed concern about the way they were admitted to hospital. Often this was through accident and emergency departments where they experienced long waits without explanation, adding to the distress and confusion frequently experienced by people suffering from a mental illness. Admissions by appointment were also often harrowing because individuals were sometimes interviewed in public places, such as the corridor.

Also, few attempts were made to reassure frightened patients – by introducing people to them, by not leaving them alone, by letting them know where they were going or what the ward procedures were. There was also an expressed need in some cases for assistance in maintaining links with the community, particularly when patients had children, but also to help maintain relationships, jobs and homes.

Safety

Many patients, particularly women, reported a feeling of fear about their own safety. There was an implication that patients' reports of assaults or threats were not always taken seriously.

Physical Surroundings

Patients were concerned about privacy, about finding a quiet place to be alone when they needed it, of somewhere private to talk to friends and relatives, of properly soundproofed telephones. Food was also seen as an important part of daily life – most psychiatric patients are physically well and so have good appetites and food is a welcome break in routine, as well as being a social occasion. Unfortunately many patients complained of poor food, little choice, rushed meal times, and unwelcoming dining areas. Personal possessions were important to patients but were not always respected. Often there was no where for them to be kept safely, or they were removed.

Hospital Staff

Having someone to talk to and who listened to them was considered very important. Patients complained that often nobody was available. Comments about medical staff were about access to doctors, about seeing them when many other professionals were present, about lack of continuity, rigid interviews and a professional reluctance to disclose information or to talk to patients. Where nursing staff were concerned, comments were made about their reluctance to talk to patients, about concern with administrative tasks at the expense of talking to patients, or the fact that only inexperienced staff were often available. The key worker system was welcome but patients emphasised their need to be informed about the way the system operates. Patients also were clear about the help that social workers could give them but felt that they were often not available when needed.

Treatment

Patients felt very strongly that choice of treatment should be available to them and that enough information should be given to enable them to participate in decisions about their treatment. They also felt that patient support and assistance groups should be encouraged rather than discouraged by staff as patients were often able to help one another. Medication was a source of concern and patients wanted information about drugs and their side effects. Ward round were universally disliked. Hospitals were often considered to be boring and the activities provided thought to be inappropriate. There were complaints that patients' reports of physical illness were often ignored. Patients were worried about their rights being infringed (eg. locked doors on open wards) and about their vulnerability after being 'sectioned'. There was a desire for impartial patients' advocates and the availability of legal advice.

Rights

Many patients felt that their views were disregarded and they were made to feel stupid and childish. Patient advocacy and patients' councils or forums were thought to be a way of helping them develop a more respected position. Also they wanted information about complaints procedures to be made more generally available and independent assistance for those who wish to make a complaint, plus the assurance that all complaints would be properly investigated.

The summary of the report written by Camden Consortium/ GPMH is given to enable indentification of the issues which psychiatric inpatients consider important. It is not a summary of the whole of this report and those involved in providing mental health services are encouraged to obtain the publication themselves (see Useful Addresses).

Those wishing to construct questionnaires for psychiatric inpatients are advised to include questions relating to the issues summarised above, and examples of relevant questions will be given later in this book, following an examination of a second weakness in the Raphael questionnaire.

2. Superficiality

The Raphael questionnaire covers a wide range of topics with very few questions. This limits the amount of detail that can be gathered on any one topic. For example, the issue of treatment is covered in four questions:

- ★ Do you see the doctors enough?
- ★ Do they tell you enough?
- ★ Do you get sufficient care from the nurses?
- ★ Do you feel reasonably free?

These four questions cover a very broad spectrum and a loose definition of the term 'treatment': there is no mention of experience of drugs or therapy, for example. Also the second question of the above four is the only one relating to information provision in the questionnaire, yet poor information provision is consistently presented by patients as an area of dissatisfaction. In fact Raphael's survey itself highlighted this as one of the main areas of criticism. About one-third of patients gave an unfavourable response to the two questions: 'Do you see the doctors enough' and 'Do they tell you enough'. Raphael remarks:

> *'Very many patients stated that they wanted to be told more about their condition.'* (p.19)

Additional questions reflecting different aspects of obtaining satisfactory information would provide more detail and show in what ways patients felt they lacked information.

In order to do this and still keep the useful short questionnaire format, however, it is necessary to divide up the topics covered into a number of short questionnaires. That is, rather than cover ward environment, treatment, work and social activities, etc. in one questionnaire, each topic is covered in a short and specific separate questionnaire.

These short questionnaires can be used in a number of different ways:

★ **Simultaneously** – to provide a 'snapshot' of user views on different aspects of the service;

★ **Alone** - to monitor a particular aspect of service delivery which is causing concern

★ **Consecutively** – as part of a rolling programme of service monitoring

★ **Together with other methods** – to explore a particular aspect of service delivery from a number of different angles.

Short, standard questionnaires for monitoring different aspects of service delivery can provide a flexible and useful tool.

What topics should these short, standard, self completion questionnaires for psychiatric inpatients cover? Some suggestions for these and for the kind of questions which should be included, can be gained by examining the work of Camden Consortium/GPMH, the Raphael questionnaire and other questionnaires. Any additions or changes of emphasis needed for different types of psychiatric inpatient (short stay, long stay and secure units, etc.), will be considered later in this chapter.

The first issue which causes patients concern is that of admission to hospital. Raphael's questionnaire does not cover this issue – perhaps because she thought patients might not be able to remember what happened to them very accurately, given the acute psychological distress which often accompanies admission and the length of time that may have elapsed, especially where long stay patients are concerned. These factors certainly need to be taken into consideration, but there is no reason why patients should not be given a questionnaire about what happened during admission after the acute phase of their illness has passed.

Some relevant questions might be as follows:

Questions about Admission to Hospital

1 When you were admitted to (ward/hospital) what route did you take?

Accident and emergency department/unit

By appointment

Other (please describe)

2 How long were you kept waiting before you were taken to a ward?

Less than half an hour

Between half an hour and an hour

Between one hour and two hours

Over two hours

Cannot remember

3 Did anyone explain to you approximately how long you would have to wait?

Yes

No

Cannot remember

4 Were refreshments available if you needed them?

Yes

No

Don't know

5 Did any staff member try to reassure you about what was happening to you?

Yes

No

Comments

6 Where were you interviewed before being admitted?

In a public place

In a private room

Other (please describe)

Cannot remember

7 Were you frightened by what was happening to you at any time during your admission?

Yes

No

Cannot remember

If yes, please describe when and in what way you felt frightened

8 When you arrived at the ward were you made to feel welcome?

Yes

No

Cannot remember

Comments

9 When you arrived at the ward were you given information about ward routine and facilities?

Yes

No

Cannot remember

10 Was there someone available to talk to you about your home situation (such as care of children, your job or house) if you needed them?

Yes

No

Did not need anyone to talk to

Cannot remember

11 Was there anything else you would like to tell us about your experience of being admitted to ____ ward/hospital?

A second major area of concern for patients is that of treatment. This is an issue which is often missed out of questionnaires because the 'doctor knows best' attitude is still widespread. However, a growing number of service providers are beginning to realise that patients are a source of valuable information about outcome of treatment.

A number of studies in the psychiatric field have taken this approach. For example, in the USA, Lee (1979) attempted to correlate comments obtained from patients about their treatment with the objective outcome of treatment rated clinically by the therapists and independently by the author. The sample comprised 36 males and 40 females randomly selected from inpatients at an open psychiatric unit at a medical centre in New York.

All 76 patients were interviewed on admission and discharge by the author and the data presented as 'patients' comments' were collected from the interview on discharge. An average interview lasted 45 minutes and patients were asked to rate the most helpful of the five aspects of hospital treatment which they received. These were:

- ★ individual psychotherapy
- ★ activities therapy
- ★ small group psychotherapy
- ★ medication (if applicable)
- ★ unit milieu.

Patients were also asked questions about why they found the treatment helpful, which people gave them most help, whether they felt their hospital stay was the right length and if they had any complaints or suggestions.

The therapist and the author independently rated the treatment outcome into one of five categories based on the clinical condition of the patient at the time of discharge compared with the baseline condition on admission. The categories were:

- ★ worse
- ★ little change
- ★ symptomatic improvement only
- ★ some personality reintegration as well as symptomatic improvement
- ★ significant positive personality change.

The conclusion of the research was that of the five treatments, the largest number of respondents viewed individual psychotherapy as the most helpful (54 per cent of the 76 patients). When admission – discharge comparison of clinical condition was considered, the patients who ranked the individual psychotherapy as the most helpful aspect of their treatment and felt that the staff were more helpful than their fellow patients, did better clinically at time of discharge than those who felt that a treatment other than individual psychotherapy was most helpful and that their fellow patients were more helpful than the staff.

A positive therapeutic relationship was considered to be a key factor in that:

> *'...the patients who did relatively well at time of discharge, are likely to say that they had a positive therapeutic relationship with their individual therapists...'* (Lee, 1979, p.53)

A similar finding was reported by Hansson *et al* (1985).

A number of other studies have been carried out in the USA and they have found a variety of different aspects of care to be important. At least two main trends can be discerned. These are: that most patients seem to have a favourable attitude towards hospital staff – 21 out of 27 studies reviewed by Weinstein in 1981 reached this conclusion; and that staff seem to be more pessimistic about the helpfulness of the treatments they offer than their patients. Dowds & Fontana (1977) in one of the studies which reported this finding comment:

> *'We believe that patients' evaluations at one month after discharge were probably influenced by the 'honeymoon' effect of at least temporary alleviation of symptoms, whereas the therapists' evaluations were more likely influenced not just by immediate symptom relief, but also by judgements of long-term change...'* (p.299)

In Britain there has as yet been few attempts to assess patients' views of their treatment. One example is the work carried out by McIntyre, Farrell and David (1989 A, 1989 B).

The study was based on an 85 per cent sample (99 subjects) who were psychiatric inpatients at an inner London teaching hospital. Patients were asked to rate how helpful they found various aspects of being in hospital and their treatment, on a five-point scale from zero (not at all helpful) to 4 (extremely helpful). Ten items were examined and these are listed here in the order of helpfulness as scored by the patients (with mean scores):

1. A free pass (2.79)
2. Visitors (2.47)
3. Talking privately to the ward doctor (2.34)
4. Talking to a nurse (2.33)
5. Medication (2.19)
6. Just being in hospital (2.02)
7. Occupational therapy (2.01)
8. The ward round (1.91)
9. Other patients (1.83)
10. Group therapy – daily meetings on the ward (1.08).

The above results are consistent with many other studies. For example, the low rating given to ward rounds was mentioned by the Camden Consortium, and Ballard and McDowell (1990) also found that 32 per cent of acute psychiatric inpatients taking part in a survey at a Coventry hospital were distressed by ward rounds even though efforts had been made to improve the situation.

The high rating given to talking to doctors and nurses echoes findings about the importance of good therapeutic relationships in many studies, including Lee (1979) mentioned earlier. As McIntyre, Farrell and David remark:

> *'This is a reminder of the importance placed upon personal contact by psychiatric patients regardless of their diagnosis and chronicity.' (p.253)*

It is clear that many inpatients, whether still receiving treatment, at discharge or after discharge, are quite capable of giving their views on different treatments. A questionnaire covering treatment could provide a useful addition to other outcome measures, as well as providing feedback on this particular aspect of service provision. Given the close link between treatment and the relationship patients have with various members of hospital staff, it makes sense to include items about staff in the same questionnaire. Some suggestions follow.

Questions about Treatment

1 Do you feel that you have been provided with sufficient explanation about the treatment you are receiving?

Yes

No

If no, what is it you would like to know more about?

2 Do you consider that you have a say in the treatment you are receiving?

Yes

No

Comments

3 Which aspect of your hospital care do you feel is doing you most good?

Please describe

4 Which aspect of your hospital care do you feel is doing you least good?

Please describe

5 Could you please tick the box which best describes your view about the following aspects of treatment:

	Very helpful	Helpful	OK	Not helpful	Very unhelpful
Ward rounds					
Medication					
Talking to a doctor in private					
Talking to a nurse					
Other patients					
ECT					
Occupational therapy					
Ward meetings					
Social activities					
Visits outside					
Free pass					
Just being in hospital					

6 Do you see the doctors in private enough?

Yes

No

Comments

7 Do the nurses have time to talk to you when you want them to?

Yes always	Yes usually	Sometimes	No hardly ever	No never

8 Do you feel that you have been given enough information about all aspects of your care?

Yes

No

If no, please mention what aspect you would like to know more about

9 Do you feel able to complain about an aspect of your hospital care, should you need to?

Yes

No

Comments

10 If you would like to make any further comments about your treatment and the nursing and medical staff, please do so here:

The last important aspect of hospital care is the ward environment and a questionnaire dealing with this should include items related to maintaining the safety, privacy and dignity of patients, questions might be as follows:

Questions about the Ward Environment

1 Do you feel safe on the ward?

Yes

No

If no, please describe your fears.

2 Do you feel that you have a personal bedroom?

Yes

No

Comments

3 Do you have a locker with a key where your belongings are safe?

Yes

No

Comments

4 Are you always able to speak to your visitors in a place where you cannot be overheard?

Yes

No

No visitors

Comments

5 Can you get away somewhere quiet on your own when you want to?

Yes

No

Comments

6 Are the washbasins, bathing and lavatory facilities private enough?

Yes

No

Comments

7 Do you feel that the ward is clean enough?

Yes

No

Comments

8 Do you like the food you are served?

Yes

No

If no, what improvements could be made?

9 Are your mealtimes here pleasant and enjoyable occasions?

Yes

No

If no, what is it that makes them unpleasant?

10 If you have any suggestions about how the ward environment could be improved please make them here:

Different Categories of Psychiatric Inpatient

Most aspects of psychiatric inpatient care have been covered under the three headings of *Admission to Hospital, Treatment,* and *Ward Environment,* but some items may be more relevant to certain categories of inpatient than others and in some cases, additional questions may be necessary. Consideration of some of these categories may make this clearer. There appear to be four main categories of psychiatric inpatient: short stay, long stay, sectioned, and secure unit.

Short Stay

Patients on short stay wards are more likely to be able to make comparisons between the kind of environment they encounter on the ward and their previous environment, than are long stay patients. A number of studies have shown that the initial experience of hospitalisation for many psychiatric patients is an unpleasant one. Weinstein (1981) suggests that some of the unfavourable attitudes expressed by many patients are due to the 'newcomer effect' – 'the feeling of powerlessness, depersonalisation, and staff abuse that attends hospitalization for the first time' (p.488).

Given the great contrast between home life and ward life that many new psychiatric inpatients feel, it would seem especially important to concentrate on admission procedure. However staff should be prepared for the fact these patients are likely to be critical if asked. Put another way, they are most able to say if issues of privacy and dignity are being neglected. The 'newcomer effect' is not just to related to homesickness, but also to the imposition of what is often an insensitive regime.

Long Stay Patients

Those who have lived in psychiatric institutions for long periods of time will find it very difficult to make comments about their hospital care because ward life has become the only life they know. These patients can be very vulnerable: not only are they likely to be afraid to make comments for fear of retribution but may also have lost the habit of thinking for themselves, or of thinking critically. Anyone providing care in such a setting may find useful the publication edited by Helen Smith: *Commitment to Quality: Safeguarding quality of care in long stay psychiatric hospitals* (1989).

Obviously the hospital admission questionnaire will not be useful with patients who have been inpatients for longer than about a year. The ward environment and treatment questionnaires should both be appropriate but some patients may need help to think and speak for themselves, so that patient advocates and patients' councils will be especially important on long stay wards.

There may also be the need for some kind of pre-discharge questionnaire to assess a hospital's ability to prepare patients for discharge into the community. Abrahamson, Swatton and Wills (1989) carried out a survey of long stay psychiatric patients on their views about leaving hospital. They found that many patients could be realistic about the advantages and disadvantages of leaving even after years in hospital, although they were handicapped by lack of information about alternatives and about the support they may expect after discharge.

Sectioned Patients

Admission as a voluntary patient entails a certain deprivation of freedom, but with compulsory treatment it is far greater. The balance of power between patient and care provider is altered to a greater degree than in the voluntary situation and many find even that difficult to cope with. Sectioned patients automatically lose certain rights and there is a risk that other rights will be eroded and abuses may occur.

Taking part in patient surveys could be considered a 'right' (the right to express an opinion or give a view). If other patients are being asked to take part, there is no reason why sectioned patients should be excluded. Many studies have included sectioned patients, including that of McIntyre, Farrell & David (1989). They found that patients who were compulsorily detained valued more highly:

> *'...visitors, amounting to contact with the outside world, and ward rounds, perhaps perceived as an opportunity to discuss and influence decisions regarding discharge.'* (p.252)

They also found that in general sectioned patients were less enthusiastic about all the treatments on offer. These differences suggest that it would be wise to make sure that the questionnaires of sectioned patients are kept separate in some way, so that any differences can be identified and will not be lost in the rest or affect the average response in a particular direction.

Given their lack of power, it is also important that these patients should have access to legal advice and an impartial patient advocate. It may be thought necessary to include additional questions relating to the patients' understanding of appeals procedure and the availability of legal advice, on questionnaires for compulsory patients.

Secure Units

If patients progressively 'offend against society' and so lose their individual rights, the value of questionnaires as a tool to obtain views lessens. Patients in secure units and to a greater extent in Special Hospitals, have opposed society in some major way and are likely to be cynical and critical about the good intentions of society's 'representatives' towards them.

The reason for obtaining feedback from patients is also likely to change. Staff will probably be more concerned about the effectiveness of the environment and treatment to rehabilitate patients than about whether patients appreciate, are satisfied with, or have complaints about, their care. The 'we know best' attitude is more justifiable when people are very disruptive or dangerous.

An example of a questionnaire study to assess the 'social climate' in order to describe the evolving milieu in a new secure unit at Towers Hospital, Leicester, has been described by Fuller (1985). Both patients and staff filled in the Correctional Institutions Environment Scale (CIES) and the researcher felt that the method

> '*... provides a rich source of information, feedback and hypotheses about the working of such a unit, including strategic issues relevant to staffing and staff morale as well as issues of patients' programme development.*' (p.77)

Such instruments may prove to be useful but they suffer from the weaknesses of all limited choice self completion questionnaires. Qualitative methods, such as interviews and group discussions conducted by independent interviewers would also seem to be necessary if more detailed feedback information is required.

Group discussions can also be a useful way for patients to prepare themselves for release into the community as indicated in a report by Burrows (1985). He describes the progress of a therapeutic group, set up by staff but run by patients, at the interim secure unit at Bethlem Royal Hospital, London.

It is encouraging to note that members of the Special Hospital Service Authority are concerned that users of this service are given the opportunity to express their views. The members are in the process of setting up a working party to decide on the best way of carrying this out.

Further Modifications to the Raphael Questionnaire

Returning to weaknesses of the Raphael questionnaire and how to overcome them, the two issues of *setting the agenda* and *superficiality* have been examined and ways of overcoming these problems have been described. Two further weaknesses remain which are weaknesses of the self completion questionnaire method generally.

3. Selectivity

A number of people are unable to complete the questionnaire: those who cannot read English, or who are illiterate; those suffering from dyslexia; those who are blind or partially sighted; those who are unable to use their hands; and those suspicious of, or confused by, forms and questionnaires. This is an important limitation, because if categories of customer are being missed their needs and views will remain unknown.

4. Lack of User Participation

The survey method is usually a one-way process in which user views are collected and no information about the results of the survey or any changes made are fed back to them. This can perpetuate the often already existing technical approach which treats users as 'objects' (in this case of survey research) rather than people. Users are not involved in exploring issues, seeking solutions to problems or making decisions about service provision – processes which treat them as human beings. These two limitations can be overcome by combining the questionnaire method with other, qualitative, approaches and methods, as discussed in Chapter 2.

The short stay inpatient context would seem to favour the option of individual interviews and/or group discussions for those patients unable or unwilling to fill in a questionnaire, backed up by a patient advocate and/or patients' council for those who decline these options or to help new patients who feel particularly helpless or confused.

Long stay patients would seem to benefit most from the existence of a patients' council, such as those existing in hospitals in Wandsworth, Nottingham and Brighton (see Useful Addresses). A patient support group of this kind may help patients used to being passive and accepting of the decisions of others, to think and speak for themselves. Without preparation even interviews and discussions may fail to overcome the passive and accepting attitude of many patients in this situation. In fact the kind of assertiveness training described by Barker (1990) may be necessary in some cases. This is training for an assertiveness which

> *'... is not interpersonal warfare and does not result in domination. Rather, it is an attempt to ensure that people live harmoniously while recognising their own needs and those of others.'* (p.38)

The aim is to improve the individual's ability to communicate, but obviously such training requires skilled and experienced personnel.

Undergoing treatment as a psychiatric inpatient can be a very demoralising and dehumanising experience. Anyone who doubts this is so should read the account written by a nurse who found herself in this situation (Anthony, 1991; also comments on her account by Barker, 1991). Listening to what patients have to say about their experiences is the first step towards improving services from the patients' point of view.

Self-completion questionnaires can be used for this task and examples have been given of suitable questions to ask. Other examples of questionnaires are available. CASPE developed an inpatient questionnaire which can be read by an optical mark reader (the PATSAT system) and are now developing one for use with acute psychiatric inpatients. The questionnaire will be based upon interviews with approximately 75 patients and will contain approximately 26 questions covering all aspects of patient care (see CASPE address in Useful Addresses).

Unfortunately many patients may be already too demoralised to assert their views and may complete questions in a less than frank manner. Patient advocacy is likely to improve users' ability to speak for themselves and it is best if the monitoring of views by questionnaire is backed up by Patients' Councils and similar organisations.

4 COMMUNITY CARE

The issue of how to obtain the views of users of community mental health services is a relatively complicated one compared to that of inpatient care. This is because community care is provided in many more ways, in different settings, and involving professionals from different disciplines.

It is important to distinguish between two aspects of getting user views on mental health services, although in practice the two aspects are closely tied together: planning service provision, and feedback about existing services.

Planning Service Provision

When the government published their consultative document 'Care in the Community' in 1981, the aim was to encourage the development of ways to ease the movement of people from hospital into community care. Central funding was available for projects under the control of Joint Consultative Committees. This process of developing different ways of providing and co-ordinating community care is still going on.

Later government documents and circulars made it clear that users should provide an important source of information about how services should be developed, as well as how they were currently operating. For example, the Griffiths Report emphasised the importance of meeting the needs of the patient and community.

As far as mental health services are concerned, guidelines have been developed and a number of different models have been proposed, but users have not always been involved in this process.

For example, Research and Development in Psychiatry (RDP) produced a guideline report – *Towards Coordinated Care* – in 1988, but users were not involved in producing it, nor in the working conference upon which it was based. The report was subsequently criticised from a number of quarters for this omission and RDP set up consultations with representatives of users' groups from different parts of the country as a result.

The document produced following the six one-day workshops involving service users – *Whose Service Is It Anyway?: Users' views on coordinating community care* (1990) differs significantly from the original document and is a good example of the importance of involving users in the consultation process.

In the Introduction to *Whose Service Is It Anyway?* the writers make it clear that their report is not simply a response to *Towards Coordinated Care,* but aims to extend the terms in which people think about the whole debate on community care. They welcomed a number of points made in the original RDP publication but they also had three major criticisms:

- ★ **Language** – the RDP report uses jargon, some of which is incomprehensible to professionals from other fields as well as to users, and some of which uses words, such as 'crisis service' and 'advocacy' which have completely different meanings to service users and professionals.
- ★ **Problem definition** – the report sees this issue in terms of lack of organisation and management which means people slip through the net and do not get the service they need. In contrast users consider their problems to be those of

poverty, poor housing and no job prospects, as well as those problems associated with traditional psychiatry, such as medication. To them it is not a problem of slipping through the net, but of there not being a net in the first place: not just management, but 'misery, poverty and a style of mental health service that offers no real choice about the type of support available'.

★ **Solutions** – the report examines technical ways of measuring quality of care, but users consider it more important to look at the quality of people's lives. They want a new version of care in the community, not 'something like a big horizontal hospital, using the same range of unpopular treatments as ever'.

The users involved in the RDP consultations have a number of suggestions for improving community care. Briefly, these are as follows:

★ Care management rather than case management – that is care workers to help users to manage their own lives wherever possible: to help them find their way through the maze of services.

★ User empowerment, through an independent funding structure for self-advocacy.

★ Information systems with users as a priority – improved user access to information about diagnosis, research evidence in alternative treatments and local services. Also the redefinition of personal information so that it belongs to the users.

★ Training for professionals structured more closely around meeting the needs of the user.

★ An overhaul of systems of social security and housing which should include providing awareness training in mental health for staff.

★ A redefinition of joint planning to encompass all key interest groups, including users, who should be involved with professionals in developing the contracts for services that authorities will be purchasing on their behalf.

★ The development of alternative models of service so that a broader range of options would be available. For example, the 'crisis card' and the 'crisis house'.

Whose Service Is It Anyway is a good guide to the kind of issues that users of community mental health services consider important and could provide a starting point. However, service providers will want to consider ways of developing a long-term dialogue with local users. There is no one way to achieve this. (See Useful Addresses and/or References for details of examples given. Also the Information Officer at Good Practices in Mental Health is a good source for examples of user group projects.)

★ Arranging consultation days and workshops on specific issues in a similar way to the approach adopted by RDP. See also 'Having a voice' from Manchester North Community Health Council.

★ The establishment of a User Forum, such as Bromley Mental Health Forum, Camden Consortium, or Islington Mental Health Forum.

★ The establishment of a User Advisory Group, such as North Manchester Community Planning Group.

★ Involving users and user representatives in planning meetings.

★ Establishing and maintaining links with local self-help and voluntary organisations.

Further information about ways of including users in service planning can be found in Winn and Quick (eds) *User Friendly Services: Guidelines for managers of community health services* (1989). A video called 'Speaking From Experience', showing examples of user involvement in Coventry, Chesterfield, Glasgow and Sussex, and a more comprehensive model from mental health services in Holland is available from Pavillion Publishing (see Useful Addresses). Those who would like to go into more depth about the whole issue of public participation in health care provision might find Maxwell and Weaver (1984) useful.

Feedback on Existing Services

Although it is useful to look at this issue separately from service planning, because most attempts to get user views are concerned with their views on *existing* services, the two issues are closely connected. Comments about the inadequacies and limitations of current services have implications for the development of future services.

Some of the most informative studies of mental health service users incorporate both aspects. There are at least two good examples of this, both dealing with services in a particular location. These are in Exeter and Birmingham.

When People Think You Are Mad They Start Behaving in Very Odd Ways: Developing services for people with severe long term mental health problems in Exeter City (Exeter Health Authority, 1987) is the report of a project which brought together quantitative data from staff providing care, and the views of service users. That is, it collected information from service providers, including how many people with long term psychiatric disabilities were known to services in Exeter City, as well as narrative information collected through interviews with 33 service users about what it was like to use those services.

The project had four main aims. These were to find out the following:

★ how many people had severe long term psychiatric disabilities in Exeter City

★ what life was like for these people, what difficulties were experienced by them and by those who supported them

★ how these people used professional and other community resources

★ what practical steps might be taken to develop services in future.

The information then collected enabled Exeter HA to make decisions about future developments in services, including the areas of: the community rehabilitation team; accommodation; improving accessibility of services; filling gaps in current services and maintaining the overall quality of services.

The Birmingham study is reported in *Keeping in Touch With the Talking: The community care needs of people with a mental illness* (Richie, Morrissey, Ward, 1988) and was carried out by Social and Community Planning Research on behalf of Birmingham Community Care Special Action Project.

The study used qualitative methods involving unstructured in-depth interviews with 67 service users. These were conducted, either individually or in small groups, with the use of a topic guide and were tape recorded.

The aims of the research were as follows:

★ to collect information on the circumstances, experiences and daily activities of individuals in different settings

★ to examine views on the relevance and adequacy of services offered or received

★ to identify needs which might be met through the development of new or extended services.

The implications for service strategies are clearly brought out by the report and, although they have a local focus, these appear to have implications for service development generally. They are as follows:

- ★ focus on people, not facilities
- ★ personalised service solutions
- ★ a broader service base
- ★ accessibility of support
- ★ range and flexibility
- ★ optimise on valued or used services.

The writers also give specific suggestions about the ways in which these general principles might be fulfilled within each of the main service areas.

Needs assessment is obviously an area which involves purchasing authorities in particular and they will find projects like the two mentioned useful. Providers, on the other hand, will be more concerned with obtaining user views on existing services.

There appear to be considerably fewer feedback studies of community services than inpatient services, and most of them are concerned with a particular service: a day centre (eg Rothwell, Lorimer and McKechnie, 1989; Turner-Smith & Thomson, 1979; Holloway, 1988) or the Community Psychiatric Nursing Service (eg Godin, Pearce and Wilson, 1987; Oyebode *et al*, 1988).

Despite the apparent paucity of examples, it is possible to make suggestions about the kind of questions to ask users based upon these examples plus the qualitative research mentioned (Birmingham, Exeter and RDP). Another extremely useful document is *Community Life: A code of practice for community care* (1990) which is the result of a panel convened by the Centre for Policy on Ageing. This code:

> *'...believes that the consumer is central to the community care bargain and should exert as much choice and as much control as is compatible with the exigencies of the public interest.'* (p.12)

It includes checklists for assessing three different regimes: domiciliary care, day care and residential care. These three divisions seem appropriate for distinguishing categories of care provision within community mental health services. Rather than attempting to suggest questions appropriate to all the many service providers (CPNS, OTS, social workers, etc.) or different types of provision (community mental health centres, mental health projects, drop in clinics, community support teams, etc.), it may be more practical to begin by describing relevant questions associated with the three main categories of service provision.

Firstly, it is worth reiterating the point that questions asked in the self-completion questionnaire format will only be useful for *monitoring* service quality and then only where people are ready, willing and able to fill in questionnaires.

Qualitative methods, such as semi-structured and unstructured interviews, are by far the best methods to use if the aim is to *explore* issues such as the quality of life of discharged patients or to discover unmet need in patients who are using some services but not others.

An interviewer who is familiar (but not currently a direct service provider) may also improve the patient's response. In a study examining patients' views about their life two weeks before and six weeks after moving from a ward in a large psychiatric hospital to a hostel, Norman and Parker (1990) found that, even though they used unstructured interviews and so gave patients a good opportunity to express themselves:

> *'The fact that the interviewer was well known and accepted by the residents was a vital factor in influencing the quality of information which residents were prepared to disclose and also allowed the interviewer to recognise any delusional elements in the residents responses.'* (Norman andParker, 1990, p.1040)

Day Care

There have been a number of studies eliciting the views of attenders at day centres and day hospitals. Turner-Smith and Thomson (1979) report one where 110 patients who had been discharged from a small day hospital in Cowes, were sent a self-completion questionnaire. This included nine structured questions and a final open question asking for comments. The nine questions asked about the patients' health since leaving the day unit, whether the unit helped them, what activities they felt helped them most, how much help they got from different types of staff, with three questions about transport to the unit.

The response rate to the questionnaire was 62.7 per cent but the researchers followed up on respondents and obtained a further 18 completed questionnaires, making a total response rate of 79 per cent. Respondents rated the activities in the following order of preference (numbers indicating the 'lot of help' response):

formal occupational therapy (44.1 per cent)

informal occupational therapy (43.1 per cent)

informal groups (37.9 per cent)

formal groups (21.9 per cent).

Rothwell, Lormer and McKechnie (1989) also carried out a self-completion questionnaire. The format used was 'How helpful did you find...?' and gave four response boxes from 'very helpful' to 'getting worse'.

Space was also provided at the end of the form for comments about what respondents found most helpful and what they wanted to complain about. Attenders and past attenders at two different kinds of day unit – an acute day hospital and rehabilitation day hospital – were collected and compared. The survey was also carried out at two community clubs and a department injection clinic.

The results show many similarities to the surveys on treatment preferences carried out in inpatient settings (see previous section). At the acute day hospital, 'Talking to nurses' was rated highest by most people with 'Seeing a psychiatrist', 'Social skills groups' and 'Occupational therapy' following in that order of rating. Medication and community group (meetings of all staff and patients twice weekly) came low down on the list. In the injection clinic, 'Talking to the nurse' was rated as being more helpful than the injection itself. At the rehabilitation unit, work placement and help with money and bus fares came out highest with medication and talking to other patients low on the list.

Attenders at day centres in East Lambeth were given semi-structured interviews which involved questions about satisfaction with the service and attitude to discharge (Holloway, 1988). In answer to the question 'In what way does (this visit) help you?' the most common category of response was that of 'Meeting people'. Nearly half of the whole sample (110 people – 95 per cent of potential respondents) mentioned this aspect of their day care as being helpful. Nearly one-third of respondents mentioned the activities available as being helpful. A fifth of respondents stated that they found the support they received from others, staff or fellow attenders, to be valuable and a similar proportion mentioned practical benefits of attending, such as the free meal. The researcher comments:

> *'The failure of attenders at the day hospitals to mention therapy as a function of their day care is intriguing.'* (Holloway, 1988, p.259)

He goes on to argue that the results indicated that users saw the value of their day care largely in social rather than therapeutic terms. For long-term attenders day care played a role very similar to that of paid work. The features of day care which received most comment in the Birmingham Community Care Special Action Project (Richie, Morrissey, Ward, 1988) were also about the people there and were usually favourable. Having somewhere to go during the day or a place where they were accepted was very important to some people, particularly those in private lodgings and hostels.

These studies give some idea of the kind of questions that it might be appropriate to ask attenders of day care units, but the less structured information obtained by SCPR and RDP also highlight other issues users considered important. These concern the extent to which users feel they have control over their lives and treatment, practical issues about money and accommodation, and information provision. If these are combined the following are some of the questions which seem important.

Questions about Day Care

1 How long have you been attending this day unit?

2 Can you get information about all you need to know here or are there some things you are finding it difficult to get information about?

Yes, I can get information about other services (eg welfare, housing) and things I want to know.

No, I would like to know about the following things (please describe).

3 Do you consider that you have a say in the running of the day unit?

Yes

No

Comments

4 Do you consider that you have a say in the treatment you are receiving?

Yes

No

Comments

5 Do you feel that you have enough social contact?

Yes

No

Comments

6 Which aspect of the day care do you feel is doing you *most* good?

Please describe

7 Which aspect of the day care do you feel is doing you *least* good?

Please describe

8 Do you think that the day unit could do something more to help you?

Yes

No

If yes, what would this be?

9 How do you travel to the day unit?

10 Are you happy about the transport arrangements?

Yes

No

If no, please describe why you are unhappy.

11 Are your mealtimes here pleasant and enjoyable occasions?

Yes

No

If no, what is it that makes them unpleasant?

12 Do you feel able to complain about an aspect of your day care should you need to?

Yes

No

Comments

13 If you would like to make any further comments about any aspects of your day care, please do so here.

Homecare

There are many more people receiving psychiatric care at home than as inpatients. Kuipers (1979) states that the majority of people with schizophrenia are living at home with a family member and are not in hospital.

There have been few studies of home psychiatric treatment in Britain and consequently surveys of those receiving home treatment are rare. A report of a service in Birmingham that provides a total psychiatric service to a community using home treatment principles is given by Dean & Gadd (1990). Although they have not yet looked at patients' views on the service provided, they intend to compare the service with a neighbouring hospital based service along several dimensions, including speed of recovery, outcome, burden to relatives and patients' and relatives' satisfaction.

Probably the most common type of care those living at home will receive is from a community psychiatric nurse (CPN). A recent survey estimated that there are around 4,990 CPNs working in the UK with approximately 130,000 people on their caseloads (White, 1990). Many CPNs are concerned about user views and have carried out surveys.

For example, Oyebode *et al* (1988) sent questionnaires to patients of two CPNs providing a service to GP surgeries in Birmingham. Of the 58 patients who responded (63 per cent), 41 felt the nurse was someone who could help with their problems, 55 found the nurse easy to talk to and 44 felt that the nurse understood their problems. These responses are interesting given that 32 said they would not have preferred to spend more time with the doctor rather than the nurse, 30 would not have wanted to see a psychiatrist rather than the nurse and 43 would not have wanted to be referred to a specialist hospital clinic. Easily accessible listening and support seem to be what many who seek help from their GP prefer.

Godin, Pearce and Wilson (1987) carried out a postal questionnaire survey of some of their clients. They found that of the 47 people who responded (42.7 per cent), 34 thought the CPN understood their problem entirely, 57.4 per cent reasonably well and 8.6 per cent not at all. The survey also asked patients questions about the convenience of visiting times, place of contact and outcome. Seventeen (36.2 per cent) felt their problems and symptoms were greatly improved, 27 (57.4 per cent) said still present but more manageable and 4 (8.5 per cent) reported no improvement. These researchers expressed satisfaction with the survey and hoped to carry out a larger survey.

It would be useful if CPNs could get together to construct a questionnaire which they could all use to assess user views of the service they provide. What kind of questions should CPNs and other providing mental health care to patients in their own homes be asking? The following are some suggestions:

Questions about Home Care

1 Do you feel you are being provided with information about all you need to know or are there some things you are finding it difficult to get information about?

Yes, I can get information about other services and things I want to know

No, I would like to know about the following things (please describe)

2 Do you consider that you have had a say in the type of service you get?

Yes

No

Comments

3 Do you consider that you have had a say in when you get the service? (the time of day, etc.)

Yes

No

Comments

4 Do you feel that you are being helped to become more independent?

Yes

No

Comments

5 Do you feel that you have enough social contact?

Yes

No

Comments

6 Do you feel that you are getting enough emotional support?

Yes

No

Comments

7 Do you feel that you are being treated with enough respect by the (nurse, social worker, etc.)?

Yes

No

Comments

8 Do you feel able to complain about an aspect of your care, should you need to?

Yes

No

Comments

9 What do you like *most* about the service you are receiving?

10 What do you like *least* about the service you are receiving?

11 Any other comments?

Relatives and other carers frequently provide an important part of the care given to patients living at home and they should also be asked for their views on the care provided by agencies. This is best carried out by means of a separate questionnaire or interview and the questions asked can be the same as those given for the direct service user, with modifications of wording where necessary. As Orford (1986) remarks, after comparing the view of relatives/carers and people with long term mental health problems about the need for occupation and accommodation, where strong disagreements exist there is a need for family therapy or intervention to work towards resolution of those disagreements.

Residential Care

In 1991, the University of Kent ran a project in Bromley to develop quality measures in residential services for people with long term mental health problems. The aim was to involve service users in defining quality indicators and one of the outcomes of the project will be to develop a mechanism for monitoring these indicators (see Useful Addresses).

Many of the questions appropriate to ask those in residential care will be similar to those in a hospital or day care setting. However, it might be assumed that as the aim is to help patients to return to as independent an existence as possible, there should be more scope for patients or residents to take control of their life. Bearing this in mind, examples might include the following.

Questions about Residential Care

1 Do you have as much control over your room as you want? (eg access, cleaning, decoration, etc.)

Yes

No

Comments

2 Can you get up and go to bed when you like?

Yes

No

Comments

3 Can you have a bath/shower when you like?

Yes

No

Comments

4 Are you given enough choice about where, when and what you eat?

Yes

No

Comments

5 Do you feel you have enough privacy in all aspects of your life?

Yes

No

Comments

6 Do you feel you have enough control over your medication/healthcare?

Yes

No

Comments

7 Do you feel you have enough control over your financial affairs?

Yes

No

Comment

8 Do you feel that you have enough social contact?

Yes

No

Comments

9 Can you get out when you want to?

Yes

No

Comments

10 Do you feel that you have enough say in what goes on in the house?

Yes

No

Comments

11 Do you feel that staff here treat you with enough respect?

Yes

No

Comments

12 Do you feel that you are being helped to become more independent?

Yes

No

Comments

13 Do you feel that you need more help or support of any kind?

Yes

No

If yes, please describe what kind

14 Do you feel able to complain about an aspect of your care, should you need to?

Yes

No

Comments

15 Are there anymore comments you would like to make about the care your receive?

The diversity of existing and possible service provision within community care makes the task of obtaining user views a complicated one. Local user forums and similar organisations which enable users and carers to give their views about the way current and future mental health services are provided, constitute one step towards solving the problem. Another is to carry out a regular monitoring of the views of current users of the different types of services using questions relevant to the three main types which have been suggested.

5 TYPES OF SERVICE USER

There are many different types of people who suffer from mental distress. It is useful to look at some of these categories separately because there may be issues specific to them. Furthermore different methods may suit different categories of service user.

Young People

When the NHS Health Advisory Service (HAS) carried out a project looking at services for disturbed adolescents in 1985, they found that services were patchy and unco-ordinated. Also:

> *'It was rare to find that young people were being involved in planning their own treatment programmes' and ' there had been few attempts to identify need in the population served.'*
> (Horrocks, 1987)

The subsequent HAS report *Bridges Over Troubled Waters* (HMSO, 1986) identified a number of examples of good practice and instigated one of their own. The Department of Child Health in Exeter had developed research techniques to identify the needs of young people as perceived by themselves, by their families and by the caring staff closest to them. They had been used to establish the needs of handicapped young people, but during 1985 HAS commissioned a similar survey by the Exeter group, of adolescents with emotional and behavioural problems.

Fifty young people and their families were asked about their individual needs and the responses they had had from the various services. Unmet needs were identified specifically by the trained interviewers. The project leader writes:

> *'The survey revealed the crucial roles of general practitioners and the schools as parts of early recognition of difficulty and as sources of support. Most families, too, recognised their need for an identifiable worker who would act as a confident and supporter in times of crisis.'* (Horrocks, 1987)

Woods (1987) also describes a project to identify unmet need. She carried out interviews with 90 fifteen year olds attending schools in Northern Ireland, using a structured interview schedule. Pupils were asked to respond 'yes' or 'no' to questions such as 'Have you ever had a problem with alcohol' as well as give a level of agreement to statements such as 'I feel under a great deal of stress'.

The researcher found some of the results worrying: 42 per cent (38) stated that they felt under a great deal of stress, 23.3 per cent (21) indicated that they had experienced some form of violence in the home.

As a result of the findings, the researcher recommended that a community based adolescent advisory service should be established. A multidisciplinary 'walk in' counselling service, based at a health centre was subsequently opened (Woods, 1987).

Apart from the needs of young people and their families, the HAS survey also discovered a high level of uncertainty among staff about the ethical and legal implications of their work. This was particularly the case in matters of consent, behaviour modification and restriction of liberty. Many of these uncertainties will have been reduced by the publication of the recent new Mental Health Code of Practice (see Childright, 1990 for a summary). This code recommends that practice for under 18-year olds should be guided by the following principles:

★ Young people should be kept as fully informed as possible about their care and treatment; their views and wishes must always be taken into account.

★ Unless statute specifically overrides, young people should be regarded as having the right to make their own decisions (and in particular treatment decisions) when they have sufficient 'understanding and intelligence'.

★ Any intervention in the life of a young person, considered necessary by reason of their mental disorder, should be the least restrictive possible and result in the least possible segregation from family, friends, community and school.

The code makes it clear that the views and wishes of young people suffering from mental distress *are* important, but as yet there are only a few examples of studies carried out to elicit their views. This may be because staff are uncertain about how capable children and adolescents are in expressing views on treatment and care. How much do they understand about what is happening to them?

Research has been carried out in the USA on children's concepts of their own psychiatric hospitalisation. Roth and Roth (1984) found that although children from 6–12 years of age did not have very specific concepts of their problems or the roles played by doctors and nurses in their treatment before psychiatric hospitalisation, they did gain insight as treatment progressed. This led the researchers to suggest that the likelihood of obtaining meaningful consent from children for psychiatric hospitalisation before their hospitalisation was not great, but as care progressed children could become more meaningfully involved in their treatment and this was particularly the case for the 9–12 year olds. They write:

> *'The data thus suggest that once psychiatric hospitalisation has commenced a dialogue can and, we believe, should be started with children about the nature of their problems, the purpose of their psychiatric treatment, and what roles the therapeutic staff members play in their treatment.'* (Roth and Roth, 1984, p.1070)

They comment that their findings cannot be generalised to include psychotic children. The children in the study were diagnosed as mainly having conduct and adjustment disorders.

The method used to elicit views in this survey of children who were six years' old was to get each child to make a series of drawings of individuals who had an important influence on his or her hospitalisation and to do so at six separate stages. After each drawing, the child was interviewed about the drawing. The interview questions were intended to reveal the child's level of understanding about what professionals and children in hospital did and what the child felt about these people and himself or herself in the hospital.

A similar combination of drawings plus interviews could be used to get children to give their views on their stay in hospital and has been suggested in McIver (1991,A).

Pyne, Morrison and Ainsworth (1986) carried out a survey of 60 adolescents (86 per cent response) and 67 parents (96 per cent response) to assess attitudes to the treatment components of a regional psychiatric unit for adolescents. They conducted the interviews using a structured questionnaire and recorded responses on a four point scale from 'very helpful' to 'made things worse'.

They found that 68 per cent of adolescents and 48 per cent of parents stated that they found the visit 'very helpful' or 'helpful'. A larger group of parents than adolescents (52 per cent v 32 per cent) reported that the unit had either 'made no difference' or 'made things worse'. Parents responded negatively to two particular aspects of the unit; firstly the treatment regime because of lack of control and care, and secondly, the unit's high family involvement and its use of family group therapy. Adolescents criticised the units siting in the grounds of a psychiatric hospital for adult patients. However the comments split the parents and adolescents into two groups, one of which valued the style of the treatment regime more than the other. This led the researchers to suggest that intake should be more selective and that units should be established with different styles of regime to suit the treatment of different disorders. They also comment on:

> *'the need to constantly appraise not only the effectiveness of treatment but the effect on the consumer...'* (Pyne, Morrison and Ainsworth, 1986, p.72)

Perhaps those caring for children and adolescents suffering from mental distress will take this comment to heart, follow the suggestions of the new Mental Health Code of Practice and'give young people a say'. They will probably need to use creative methods, such as encouraging drawing and storytelling combined with interviews, for children up to twelve years old. Many adolescents can probably cope with questions or structured interviews but may prefer to 'have their say' in a less formalised way. Encouraging feedback through plays, drawings, stories, etc. would probably be more valuable and beneficial. It may sound unscientific, but psychologists are quite capable of devising ways of validating concepts and feelings expressed pictorially and in other non-verbal ways.

Black and Minority People

Surveys frequently fail to obtain the views of black and minority people. For example, researchers carrying out a postal survey of residents in the area served by Wycombe Health Authority achieved a 73 per cent response rate but they commented:

> *'there was a total lack of interest on the part of the ethnic minorities, despite requesting help from the local community liaison officer.'* (Barr and Rogers, 1991)

White health professionals and researchers new to the area of race relations are often disappointed that their genuine attempts to get the views of black and minority users are unsuccessful or, even worse, met with hostility. Reading reports such as *Mental Health Care for Ethnic Minority Groups* (GPMH, 1988) and *Is Race on Your Agenda?* (Christie and Blunden 1991) will help to develop an understanding of the complexity of the area.

Lack of contact can even occur when qualitative research methods are used. In 1987 Birmingham Community Care Special Action Project ran a series of programmes for the City Council. These meetings were unsuccessful in attracting significant participation by more than a handful of either Afro-Caribbean or Asian carers, despite the availability of interpreters, contact with community groups, temples, mosques etc. The experience sparked a development project to identify effective methods of making contact with Afro-Caribbean and Asian carers and to increase understanding about the needs of carers from these communities.

Community workers and representatives suggested that poor attendance could be explained by factors such as unfamiliarity with this kind of meeting, bad experiences with County Council services, and fear of officialdom. Possible ways forward were suggested by more use being made of community groups, local churches, temples and mosques, and local press and radio to contact carers.

The Development Project tried out the recommended approaches but found they produced little response. Contacts established via service providers proved most useful. The project workers comment:

> *'It has ... become clear that the process of building up confidence and gaining access to the often very tightly knit networks in the Afro-Caribbean and Asian communities, takes time, commitment and a high level of sensitivity to and understanding of religious and cultural tradition. A variety of methods of approach must be adopted which take account of the extent to which inability to read English or mother tongue is a relatively common experience.'* (Jowell, Larrier and Lawrence, 1990)

Their recommendations to the City Council included the development of a pro-active information strategy where information is developed in and disseminated to ethnic communities as part of a mainstream information programme. Also that projects such as theirs should be part of the City's maintstream activities, rather than being conducted as a discrete short-term activity.

Other studies have indentified a number of barriers to communication between black and minority communities and public services. Some of these are:

★ lack of an equal opportunities employment policy within the service

★ lack of staff training for working in a multi-racial society

★ lack of information about the different black and minority groups living in the area

★ lack of formal links with black and minority communities (eg working parties, liaison groups, and forms of consultation)

★ lack of well established informal links with black and minority groups (eg a development worker who has built up good contacts with local people)

★ lack of responsiveness to information obtained from black and minority service users.

Where mental health services are concerned, further issues have been identified. These include:

- ★ **Fewer treatment options** – black and minority groups consistently receive higher doses of drugs, more ECT, less individual attention from consultants and less psychotherapy
- ★ **Inappropriate treatment** – due to cultural misunderstanding. For example, not taking into account the over-riding obligation to parents felt by Chinese people
- ★ **Language difficulties** – interpreters can alter the direction of a sensitive interview and mental health work depends upon the establishment of a meaningful relationship between worker and client
- ★ **Differences in diet** – the wrong food can increase mental distress, particularly if religious observances are involved
- ★ **Lack of knowledge** – about services, their aims and activities, choices available, etc.

Given the barriers to communication, it is unlikely that a questionnaire survey designed to canvass views generally will be sensitive enough to elicit the views of black and minority users. Each of the barriers will have to be removed before this can take place.

Research aimed at obtaining information about the needs and experiences of black and minority groups will have to be much more carefully designed to reach these groups and listen to them. A good example is Leicester Black Mental Health Groups' work reported in *Sadness in My Heart: Racism and Mental Health* (University of Leciester, 1989 – see Jeyasingham, 1990 for a summary).

The researchers interviewed two main groups of people; black patients diagnosed as schizophrenic, their parents and siblings; and Asian women suffering from depression.

One of the most important aspects of their research is to draw attention to the way that racism relates to the mental distress of black people. They report that the experience of racism in mental hospitals is 'too easily overlooked' in the treatment of black people, and

> *'Distressed by admission and illness, racism added considerably to the pain of hospitalisation and reinforced the overwhelming sense of isolation, of loneliness felt by everyone with whom we talked.'* (p. 45)

The researchers found that racism was a central motif in the ways in which the black people they interviewed reconstructed the events of their lives. For some individuals there was a crisis of black identity and an evident unease with their blackness which was a recurring theme of the accounts:

> *'It is a painful process of alienation from self engendering in some forms of self-hate which have been detrimental to mental stability and the 'normal' processes of life.'* (p.55)

Detailed information of this kind can only be gathered using qualitative methods such as interviews and group discussions.

Sadhoo (1990) carried out interviews with Afro-Carribbeans who were referred and admitted to a psychiatric hospital in Wandsworth. She writes that 'Consumer's perceptions regarding the social and psychiatric services they encountered were overwhelmingly negative'. See also the results of a research project carried out by the Black Mental Health Group in Lewisham, published in *Positive Thinking for Mental Health* (1991).

Another way of doing this is to establish a Black and Ethnic Minorities Mental Health Forum such as the one in Haringey (Kalsi and Constantinides, 1989). Initiatives established by the Forum include: gathering information about mental health services in the district with a view to producing a user guide in several languages; setting up a patient advocacy or befriending scheme; setting up on 'ethnic switchboard' to give users advice on mental health problems and where to go for help; providing better information on the availability of after-care services and designing a system for monitoring by ethnic origin the users of in-patient psychiatric services, the kinds of diagnoses made and treatment offered.

Young and elderly people suffering from mental distress have been considered separately in this chapter and these two categories also require special mention within black and minority groups. The Health Advisory Service study found that it was a standard response in District Health Authorities that young people from ethnic minority groups posed 'no particular problems' but there had rarely been any attempt at ethnic monitoring.

A report produced as part of the Community Care Project carried out by the University of Birmingham for Central Birmingham health authority (Evers et al, 1988) draws attention to the fact that despite predicted increases in the number of elderly people from ethnic minorities, the issues involving in meeting their health and service needs have not been adequately addressed. Studies have tended to focus on physical rather than mental ill health and there appear to be few studies of mental health among older black and minority people. Research on carers of those with dementing illness is also confined to white people.

The Community Care Project work included open ended interviews with 66 clients, of which nine clients thought to be either demented or mentally impaired were from ethnic minority groups (four Asian men, four Afro-Caribbean men and one Afro-Caribbean woman). Just one client was over the age of 75. In contrast, the random sample of clients with either dementia or mental impairment consisted of 68.8 per cent women and only 31.6 per cent were under 75 years old. The demented clients from ethnic minorities were therefore younger, and more likely to be male than the whole sample. The researchers comment:

> *'The research has raised interesting issues regarding the nature of dementia among black clients, and the response of statutory community services to these people. Even in inner-city areas with a high proportion of residents from ethnic minorities, few are known to the community services.'* (Evers et al, The Community Care Project Report, No.10, p.11)

Those involved in obtaining the views of service users should neither try to avoid the issue of getting black and minority views, nor underestimate the complexity of the task. They need to ensure that all barriers to communication, such as those mentioned above, are overcome before expecting to collect accurate and useful information. It is also important that they do not fall into the trap of assuming that all black and minority populations and different age groups have similar views and needs.

There is a growing body of information on these issues and health professionals should try and make as much use of it as possible. Organisations can be found listed under 'Useful Addresses'. A reading list on race and mental health can be obtained from the Community Living Development Team at the King's Fund Centre, which also has a project worker developing and supporting projects in this area.

Elderly People

Of all the different types of peoples suffering from mental distress, the elderly, and in particular those suffering from dementia, would seem to be the least able to evaluate and give their views about services. Elderly people consistently give very favourable responses to questions about their health care because they have known a time without the NHS. Many just 'don't want to complain or cause any trouble'. Those with short-term memory loss – a typical feature of dementia – also find it hard to describe the experiences they have had with the services provided. Despite these problems there are two really excellent studies which show that useful information about service requirements can be obtained from even those who appear to have severe communication difficulties.

The first study, reported in 'Consulting with Service Users: A Project in Brighton West for EMI Services' (Clare Fisher, 1989) involved interviews with a total of 60 users, 10 carers and staff at all levels. In the first stage of the project, unstructured interviews were carried out with ten of the more articulate users in order to try to identify their main concerns and the issues of most importance to them. These issues were divided into six sections, each involving several questions, which formed a semi-structured interview schedule, which was then used to interview a further 50 service users in various settings. The researcher comments:

> *'..considerable time was spent in general conversation to gain their confidence and see how best to communicate further where appropriate, very simple questions were asked that could be answered by a shake or nod or by pointing to a simple scale.'* (p.8)

The results were summarised under the six headings used in the interview schedule. Briefly these were as follows:

- ★ **Information** – many users felt some confusion about the reasons why they had been referred to each place. In general most felt they had little choice about where they went. An approachable personal contact who could sort out queries was considered to be of most help in providing information.
- ★ **Features** – users were not usually in a position to compare different facilities and tended to be grateful for what there was. Issues were raised about food, especially the way it was served, and about security for personal belongings.

- **Social** – staff in all places were very highly praised by users who generally have tremendous appreciation for what is done for them. The main criticisms concerned staff turnover, because users prefer a stable environment, and insufficient individual attention.
- **Treatment** – users seemed to have difficulty obtaining sufficient information and were often 'remarkably apologetic' about what they wanted to know. The situation was improved where a key-worker had taken the responsibility to ask if the user had any queries and helped them through the system.
- **Satisfaction** – in general, most people were more than satisfied with the services they experienced, one exception was the ambulance service that carried people to and from a day hospital.
- **Coordination between services** – 'who ends up where can seem like a lottery' and individual care can seem dislocated, with much confusion and duplication.

Interviews were also carried out with carers as users of service in their own right rather than as spokespersons for their relatives. The research confirmed that carers do experience the service differently from direct service users. One of their major needs was for easily accessible information. They also valued voluntary groups to help with many issues, such as coming to terms with accepting help, taking care of themselves, and thinking about the future.

The researcher concludes the study by making a comment about the difficulties involved in getting the views of this type of user:

> *'many EMI service users, because of the nature of their problems, will never be able to make much contribution to the running of services themselves and could never take up self advocacy ...maintaining consultation and working towards participation must be actively encouraged.'* (p.28)

The following suggestions to encourage participation are made in the report:

- a working group at sector/district level
- users meeting at unit/ward level
- an advocate to work with EMI individuals across an area
- key worker/individual worker to improve personal relationships with users and on-to-one basis
- further project work in areas still not addressed, such as the views of ex-users and those who use community based services, perhaps using a case study approach following a limited number of users from the time of their referral to the service over a set length of time.

The second study involves elderly people with dementia living at home, but the approach adopted is one which can be generalised to other users, particularly those with chronic illness living at home. *Consulting consumers in the NHS: A guideline study* (National Consumer Council, 1990) includes checklists, questionnaires and performance indicators to enable service providers to carry out their own research in this area.

The study, carried out by Social and Community Planning Research (SCPR) for the National Consumer Council, involved interviews with 15 elderly people suffering from dementia, and 43 carers. Descriptions of the effects of the illness were collected and then the researchers considered what the suffers and their carers needed from service providers in order for the sufferers to remain in the community and their carers to remain looking after them. Three main areas of need were identified:

- help with everyday tasks
- supervision to ensure their own and other people's safety
- social contact, support and reassurance.

The researchers argue that from the sufferer's point of view all three functions would, ideally, be fulfilled by the care of one person, preferably a familiar loved person, so that the important issue to tackle is: '...how to support the carer in his/her role in providing for the sufferer; or where there is no carer, what support is necessary for the sufferer to continue to live at home.' (p.27) As far as carers were concerned, the most frequently mentioned areas of need or gaps in provision were:

★ early diagnosis
★ information and advice, especially at the early stages
★ counselling
★ a sitting service
★ information about possible residential care (for long term planning)
★ a prompt, reliable ambulance service (for those attending day units).

The researchers conclude their study by stating:

> *'...we believe that we have devised checklists and questionnaires which both professionals and patients can and must use if an evaluation of the effectiveness of a service is to get to the heart of what matters in service provision.'* (p.61)

Examples of appropriate methodological approaches to elderly people suffering form mental distress, and their carers, including questions to ask and service checklists, are available. Those who provide services to this client group, either in a residential or community setting, should be able to adopt the methods used in the Brighton Health Authority and National Consumer Council work to their own use. Also they are advised to follow the example given in the Brighton research and treat carers as service users in their own right. A nationwide survey of carers, *Crossroads Care Report* (Crossroads Care, 1990) may also provide useful information about carers, as will the leaflet *Carers' Needs*, a ten point plan for carers and guidelines for good practice (see Useful Addresses).

[illegible] an area.

[illegible]

[illegible] by the care of one

6 CONCLUSION

The many studies and initiatives covered in this publication have demonstrated the extent to which useful information can be gathered from users and ex-users of mental health services. Those who were worried about the task should now have an idea of where to begin and how to proceed.

Those working at purchaser level will have gained an understanding of what constitutes good user feedback and will be able to use this to inform contracting negotiations. They will also have been made aware of some of the issues involved in consulting users about planning services which more closely resemble the type of service users want.

Those working at provider level will have found that although wider issues surrounding the treatment of those suffering from mental distress makes the process of obtaining reliable and valid views a complex one, it is not impossible. The way forward is to set up procedures for encouraging patients to speak for themselves and understand their potential role in improving and monitoring service quality. This can be achieved through developing practices such as assertion training, patient's advocacy and patient's forums.

In addition to being a source of patients' views these procedures will help to improve the quality (validity) of the information collected during quantitative exercises, such as questionnaire surveys, which are aimed at collecting the views of a representative sample of users.

It should be remembered, however, that the use of a sophisticated approach to collecting user views is in itself not a guarantee of service quality, although it is a substantial step in the right direction. User views should form the basis for service change and this requires the development of a customer service oriented culture. This can be particularly difficult where mental health services are concerned because of a prevailing view that patients suffering from mental distress are unable to know what is best for them because their illness affects their reason. A programme of training to help staff change their attitudes, knowledge and behaviour will aid this development.

7 CHECKLIST OF QUESTIONS TO ASK SERVICE USERS

Inpatient Care

1) Questions about Admission to Hospital

1 When you were admitted to (ward/hospital) what route did you take?

Accident and emergency department/unit

By appointment

Other (please describe)

2 How long were you kept waiting before you were taken to a ward?

Less than half an hour

Between half an hour and an hour

Between one hour and two hours

Over two hours

Cannot remember

3 Did anyone explain to you approximately how long you would have to wait?

Yes

No

Cannot remember

4 Were refreshments available if you needed them?

Yes

No

Don't know

5 Did any staff member try to reassure you about what was happening to you?

Yes

No

Comments

6 Where were you interviewed before being admitted?

In a public place

In a private room

Other (please describe)

Cannot remember

7 Were you frightened by what was happening to you at any time during your admission?

Yes

No

Cannot remember

If yes, please describe when and in what way you felt frightened

8 When you arrived at the ward were you made to feel welcome?

Yes

No

Cannot remember

Comments

9 When you arrived at the ward were you given information about ward routine and facilities?

Yes

No

Cannot remember

10 Was there someone available to talk to you about your home situation (such as care of children, your job or house) if you needed them?

Yes

No

Did not need anyone to talk to

Cannot remember

11 Was there anything else you would like to tell us about your experience of being admitted to ____ ward/hospital?

2) Questions about Treatment

1 Do you feel that you have been provided with sufficient explanation about the treatment you are receiving?

Yes

No

If no, what is it you would like to know more about?

2 Do you consider that you have a say in the treatment you are receiving?

Yes

No

Comments

3 Which aspect of your hosptial care do you feel is doing you most good?

Please describe

4 Which aspect of your hospital care do you feel is doing you least good?

Please describe

5 Could you please tick the box which best describes your view about the following aspects of treatment:

	Very helpful	Helpful	OK	Not helpful	Very unhelpful
Ward rounds					
Medication					
Talking to a doctor in private					
Talking to a nurse					
Other patients					
ECT					
Occupational therapy					
Ward meetings					
Social activities					
Visits outside					
Free Pass					
Just being in hospital					

6 Do you see the doctors in private enough?

Yes

No

Comments

7 Do the nurses have time to talk to you when you want them to?

Yes always

Yes usually

Sometimes

No, hardly ever

No never

8 Do you feel that you have been given enough information about all aspects of your care?

Yes

No

If no, please mention what aspect you would like to know more about

9 Do you feel able to complain about an aspect of your hospital care, should you need to?

Yes

No

Comments

10 If you would like to make any further comments about your treatment and the nursing and medical staff, please do so here:

3) Questions about the Ward Environment

1 Do you feel safe on the ward?

Yes

No

If no, please describe your fears

2 Do you feel that you have a personal bedroom?

Yes

No

Comments

3 Do you have a locker with a key where your belongings are safe?

Yes

No

Comments

4 Are you always able to speak to your visitors in a place where you cannot be overheard?

Yes

No

No visitors

Comments

5 Can you get away somewhere quiet on your own when you want to?

Yes

No

Comments

6 Are the washbasins, bathing and lavatory facilities private enough?

Yes

No

Comments

7 Do you feel that the ward is clean enough?

Yes

No

Comments

8 Do you like the food you are served?

Yes

No

If no, what improvements could be made?

9 Are your mealtimes here pleasant and enjoyable occasions?

Yes

No

If no, what is it that makes them unpleasant?

10 If you have any suggestions about how the ward environment could be improved please make them here:

Community Care

1) Questions about Day Care

1 How long have you been attending this day unit?

2 Can you get information about all you need to know here or are there some things you are finding it difficult to get information about?

Yes, I can get information about other services (eg welfare, housing) and things I want to know.

No, I wuld like to know about the following things (please describe).

3 Do you consider that you have a say in the running of the day unit?

Yes

No

Comments

4 Do you consider that you have a say in the treatment you are receiving?

Yes

No

Comments

5 Do you feel that you have enough social contact?

Yes

No

Comments

6 Which aspect of the day care do you feel is doing you *most* good?

Please describe

7 Which aspect of the day care do you feel is doing you *least* good?

Please describe

8 Do you think that the day unit could do something more to help you?

Yes

No

If yes, what would this be?

9 How do you travel to the day unit?

10 Are you happy about the transport arrangements?

Yes

No

If no, please describe why you are unhappy.

11 Are your mealtimes here pleasant and enjoyable occasions?

Yes

No

If no, what is it that makes them unpleasant?

12 Do you feel able to complain about an aspect of your day care should you need to?

Yes

No

Comments

13 If you would like to make any further comments about any aspects of your day care, please do so here.

2) Questions about Home Care

1 Do you feel you are being provided with information about all you need to know or are there some things you are finding it difficult to get information about?

Yes, I can get information about other services and things I want to know

No, I would like to know about the following things (please describe):

2 Do you consider that you have had a say in the type of service you get?

Yes

No

Comments

3 Do you consider that you have had a say in *when* you get the service? (the time of day, etc.)

Yes

No

Comments

4 Do you feel that you are being helped to become more independent?

Yes

No

Comments

5 Do you feel that you have enough social contact?

Yes

No

Comments

6 Do you feel that you are getting enough emotional support?

Yes

No

Comments

7 Do you feel that you are being treated with enough respect by the (nurse, social worker, etc.)?

Yes

No

Comments

8 Do you feel able to complain about an aspect of your care, should you need to?

Yes

No

Comments

9 What do you like *most* about the service you are receiving?

10 What do you like *least* about the service you are receiving?

11 Any other comments?

3) Questions about Residential Care

1 Do you have as much control over your room as you want? (eg access, cleaning, decoration, etc.)

Yes

No

Comments

2 Can you get up and go to bed when you like?

Yes

No

Comments

3 Can you have a bath/shower when you like?

Yes

No

Comments

4 Are you given enough choice about where, when and what you eat?

Yes

No

Comments

5 Do you feel you have enough privacy in all aspects of your life?

Yes

No

Comments

6 Do you feel you have enough control over your medication/healthcare?

Yes

No

Comments

7 Do you feel you have enough control over your financial affairs?

Yes

No

Comments

8 Do you feel that you have enough social contact?

Yes

No

Comments

9 Can you get out when you want to?

Yes

No

Comments

10 Do you feel that you have enough say in what goes on in the house?

Yes

No

Comments

11 Do you feel that staff here treat you with enough respect?

Yes

No

Comments

12 Do you feel that you are being helped to become more independent?

Yes

No

Comments

13 Do you feel that you need more help or support of any kind?

Yes

No

If yes, please describe what kind

14 Do you feel able to complain about an aspect of your care, should you need to?

Yes

No

Comments

15 Are there anymore comments you would like to make about the care you receive?

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