

Making a reality of user involvement in community mental health services

Kamaldeep Bhui, Anne Aubin and Geraldine Strathdee

User centred services as an ideology have not become a reality of everyday clinical practice. In this paper we introduce a series of articles which describe user centred practice in a south London community-based rehabilitation service for the severely mentally ill. We emphasise the medical consultation style adopted, the service management style and specific initiatives allowing users to influence our practice and shape functional and structural components of the service.

An evolving body of research demonstrates that users are not satisfied with current practice in mental health services (Rogers *et al.*, 1993; Wood, 1994) in spite of Department of Health guidelines which emphasise that services must be responsive to patients' identified needs (Department of Health, 1989). Consumer audit has developed as a practical way to elicit opinions so as to optimise outcomes (Dennis, 1995); this is a time consuming process with no guarantee that the recommendations will be adopted and systematically operationalised within a sensible time frame. The impact of users' wishes on actual service developments is therefore reduced even though there is an ideological satisfaction that a consultation process was responsibly undertaken and measures of need were obtained.

This is one of a series of papers describing user involvement in daily clinical practice in a south London rehabilitation and community care service for the severely mentally ill. In the paper we present a brief overview of the service, the medical consultation style adopted, the service management style and examples of specific initiatives allowing users to influence our practice and shape functional and structural components of the service. Making user involvement a reality involves: developing joint information; three-way good practice workshops; mandatory involvement in the Care Programme Approach (CPA); care management; hospitality and making one practical change after each consultation; adapting individual consultation style; representation on planning groups; designing new services/environments; users in staff training;

and user representatives on appointments committees.

The service

The service is based in a deprived inner-city area with a population of 47 000. It now includes four continuing care hospital beds, nine beds in community houses for crisis care, respite, and for resettlement while on forensic sections, a planned development of four beds in a 24-hour, seven-day staffed home and a six single bed-sitter house. A detailed account of the service ideology, including range, structural and functional components and interagency alliances has previously been given (Myers-Davis *et al.*, 1994; Foulds *et al.*, 1998).

Illness self-management

Even with illnesses regarded as having a predominantly biomedical aetiology, problems with 'treatment compliance' and effective illness management can be traced to differences between patients' explanatory models of illness and the biomedical model (Heurtin-Roberts & Reisin, 1992). In the realms of psychiatric disorders, social and cultural factors significantly influence the assessment, presentation and treatment; the users' perspective therefore warrants significant attention. Effective clinical management involves both education and interventions that range from simple single strategies to complex multimodal approaches in which the patient's role may vary from being a passive participant of professional supervision to complete autonomy and self-care (Blackwell, 1992). Modularised teaching of illness self-management skills to people with schizophrenia appears to operate independently of baseline psychology and symptom improvement (Eckman *et al.*, 1992). Warnes *et al.* (1996) describe a range of coping strategies, developed by Ann Warnes empirically, to regain control over her life. Such strategies are not dissimilar to cognitive and behavioural

treatments which can lead to significant relief from persistent psychotic symptoms (Chadwick & Birchwood, 1994; Kingdon, 1994).

The medical consultation

Patients with a chronic mental illness have encountered a diversity of professional consultation and treatment styles. However, consultations are influenced not only by profession-based knowledge but also by the personality, charisma and experience of the clinician. We have found the need to learn a more negotiating style of consultation. The usual medical approach of collecting a detailed history, although the pinnacle of good practice, is usually met with frustration and sometimes the fracturing of any potential treatment alliance (Ross *et al.*, 1993). Patients report not feeling human and valued as they are asked to repeat a catalogue of events which have been well documented and to respond to a variety of baffling questions (Wood, 1994). They feel excluded from actively participating in a consultation and remain as powerless as when not in contact with professionals (Ross *et al.*, 1993). It is evident that no one style suits all patients and so coming to know the likes and dislikes of each patient is imperative.

Content of consultations

In order to ensure continuity of care each patient is allocated a keyworker and a doctor. The professionals clarify with each patient their respective roles and the duration of their time with the team. The careful choice of care coordinator and doctor is determined by the patients' needs profile (social and cultural) and the necessary frequency and duration of contact. Having at least two individuals working with a client reassuringly maintains some consistency of approach. If the risk of relapse is especially high or the consequences of relapse involve danger to the public or the patient a further co-worker is also allocated. For a patient who has great difficulty working with new members of the team, he or she will feel supported in spite of unexpected staff absences. The multi-disciplinary health record of each continuing care patient has a detailed typed summary of the past history and a review of previous medical, social and psychological treatments and their effectiveness. A list of symptoms of relapse and specific treatment strategies which have proven effective at times of crisis, life events or non-compliance are documented and all contained in the front of the file along with a record of CPA arrangements. This obviates the need for detailed histories to be re-obtained and attention can be focused on presenting problems and on what the patient or

carer wants out of a therapeutic encounter. Effective communication may still be interrupted by difficulties of attention, concentration, cognition, affect, hallucinatory experiences and of course interruptions (bleeps, telephone calls, etc). Once a stable and optimal combination of medication has been identified, changes are only introduced if specific alterations have previously proved effective during any natural fluctuation of symptoms or at times of crisis, and have been agreed with the patient as part of a crisis plan. User involvement in issues around medication involves: individual tailoring of medication; the minimum effective dose; frequent review; acute, crisis and maintenance doses; new, expensive but less toxic drugs; and safe, supported drug reductions and holidays if the patient and professional accept the risk of relapses is outweighed by a desire to achieve greater mastery over symptoms.

We emphasise user control over the illness and informed choice about treatment options. This may occasionally see a choice that we have not recommended. Such situations are met with a careful risk assessment of potential pitfalls and a crisis plan agreed and implemented immediately. The level of monitoring and support, for example, may be increased by agreeing more day care or an evening group. The illness is relegated to one part of a patient's life and we focus on other positive roles. Comparison with risk assessment in the control of other conditions (blood pressure and diabetes) and the deployment of written or tape recorded advice encourages patients to actively interact with their illness and explore the limitations of their influence over its course. Once signs of relapse are successfully characterised by patients in the course of their daily lives, we devote much time to practising coping strategies based on our own professional experience but also recruiting the experiential expertise of the patient (Warnes *et al.*, 1996). Users are involved in writing their care programme and their CPA reviews.

Users as planners of services

Users have expressed the desire for an equal partnership with statutory organisations in the service planning, development and implementation process (Wood, 1994). Yet in some instances professional opinion and service demands are such that user participation is not pursued with enthusiasm. Furthermore, carers' and relatives' views may be at variance with local community care policy (Vicente *et al.*, 1993). The legislative framework within which professionals and agencies must operate dictates the degree of flexibility and therapeutic risks that professionals and statutory providers can take regardless of their

personal convictions (sympathetic or not) about user involvement. Examples of community services deploying consumers as providers of a service report that many operational issues such as role definition, task identification and line management, require further scrutiny (Dixon *et al.*, 1994). Reassuringly, the families of patients receiving care by a consumer are no less dissatisfied than those families and patients receiving care by standard case management services (Soloman & Draine, 1994). These determined efforts to involve users for the benefit of other users are likely to raise significant concerns among professionals about confidentiality, training and public perceptions of the quality of care delivered. Perhaps now is the time for a more creative approach, especially as we have no evidence to suggest that there are any insurmountable obstacles.

Development of good practice guidelines

One example of users shaping practice was a series of three-way (user/carer/professional) workshops held to establish the most useful content of printed leaflets to encourage users to get the best out of an out-patient appointment: make sure users and keyworkers had the same agenda; and make the best of the first hours in hospital should they be admitted. Participants openly discussed their objections to current practice. The wording and format of the leaflets were adjusted in accordance with users' preferences. The professionals involved learned of the patients' priorities and dislikes about the consultation process. For example, appointments that conflict with other appointments (housing, benefits, physical health), early morning appointments for some people are impossible to keep because of the sedative effects of their medication; appointments at less busy times (at the day site) encourage them to attend without the fear of becoming anxious due to the pace of other day-site activities. Some patients request reminders by phone, letter or a personal home visit. These are accommodated with the long-term therapeutic relationship in mind, avoiding self-imposed isolation but at the same time maximising the client's functional capacity. Such a focus of negotiation can then usefully become a part of therapeutic work. In a weekly user centred site meeting users openly criticise aspects of the services and joint plans are made to bring about change. Hearing information from fellow patients tends to surmount the barriers that traditionally had prevented users from being frank with their doctor or nurse. Thus the placing of furniture, the opening times, the range of music played on the site, the choice of day

outings and attendance at leisure facilities have all been shaped as a direct result of patient requests. A video outlining the range of treatments in schizophrenia and how best to manage your doctor was recently made with some sponsorship from a pharmaceutical company. The users contributed to the making (as interviewees) and final editing of this so as to shape the final impact on the viewer.

Policy and management

The rehabilitation team and the acute services hold monthly strategy meetings to which a user representative is invited. Participation is encouraged and feedback is given to the other users about problems within local services which managers and clinicians are trying to address. To make such participation effective certain general principles need to be followed:

- (a) Pre-meeting talking through the agenda
- (b) Support in the meeting if distressed
- (c) Slower pace of the meetings
- (d) Explaining acronyms, jargon and processes
- (e) Providing administrative and secretarial support
- (f) Choosing the environment.

At times of service restructuring users are often considered last, even though it is their 24-hour living environment that is being altered. Anticipating the impact of such changes enables informed service users to anticipate problems they and the professionals may encounter.

How far is it sensible to persist with user empowerment?

Some would argue that the customer is not always right and that professionals should retain ultimate say over a patient's treatment. Using the approach we have adopted, the professional shares some of the responsibilities for choice about treatment options with his or her patient enabling a more individualised consideration of the options rather than assuming all patients benefit in a similar way following a specific intervention. Fears persist about how much control professionals actually have over patient management while they are still expected to take full professional and legal responsibility for treatment. Our experience is that we are constantly re-educated by users about their uniqueness and how one cannot generalise about treatments and automatically apply knowledge gained from studies on large numbers of people in specific circumstances to particular individuals. This may seem a simplistic view yet it parallels similar assertions by public health

physicians and epidemiologists (Rose, 1985; Loomis & Wing, 1990).

Conclusions

Although our concepts of mental disorder, preferred service structures, acceptable interventions, professional ethics and medico-legal constraints are constantly challenged we believe that this is in the best interests of service users. Professionals must ensure that any resistance to change is truly informed by the evidence to date, but not at the expense of allowing the absence of evidence to hamper creative solutions.

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*Kamaldeep Bhui, Senior Registrar, Maudsley Hospital, London; Anne Aubin, Research Fellow, Institute of Psychiatry; and Geraldine Strathdee, Consultant Community Psychiatrist, Maudsley Hospital

*Correspondence: Dr K. Bhui, Wellcome Training Fellow, Institute of Psychiatry, De Crespigny Park, London SE5 8AZ