editorials

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Involving users in the development of psychiatric services – no longer an option†

It is 16 years since Griffith's report recommended that consumers of health care should be involved in future developments and evaluation of services provided by the NHS (Department of Health, 1989). During the intervening period successive governments have sought to strengthen the role of patients as active participants in their relationship with those who provide services. Individual service users have also become more informed about treatment options and are increasingly aware of their rights as consumers of health care (Campbell, 2000).

The medical profession has often appeared reluctant to embrace these changes, which challenge traditional beliefs of doctors that their skills should be measured by examining the impact of their treatment on symptoms of ill health rather than on whether or not the patient feels they have benefited from the care they receive (Pfifferling, 1980). This reluctance is illustrated by resistance to accepting that the views of service users can form a valid basis for judging service outcome (Crawford & Kessel, 1999) and continuing reluctance to accept user involvement in training junior doctors. Despite this there are signs that professional attitudes are shifting. The British Medical Association, in attempting to define core values for the medical profession in the 21st century, is recognising that paternalism is no longer an appropriate model for the doctor–patient relationship (British Medical Association Secretariat, 1994). Instead, it is argued that the relationship should be a 'partnership of mutual trust' in which doctors should encourage patients to help decide treatment and care.

Psychiatrists have argued that special factors, related to the needs of the patients they see, effect the extent to which users of psychiatric services can or should be regarded as consumers. First, concerns are expressed about whether a service user whose insight is affected by illness can play the role of consumer. Second, it is argued that psychiatry has a dual function in which the needs of service users have to be balanced with a wider responsibility to society at large (Eastman, 1999). Concern about the role of user groups in developing psychiatric services has also been expressed. Whatever the validity of these concerns, there is no sign that they will prevent the increasing involvement of service users in shaping developments in psychiatric practice.

The National Service Framework for Mental Health and the role of service users

The National Service Framework for Mental Health is an attempt to set national standards for services for people of working age who experience mental illness (Department of Health, 1999*a*). Service users were involved in setting these standards and the document identifies service users as key players in the development and evaluation of health care. Specifically, the document states that:

(a) Service users need to be involved in developing services in order to make them more acceptable and culturally sensitive.
(b) Performance of psychiatric services needs to be assessed at a national and local level by the experience of users and carers including those from Black and ethnic minority groups.
(c) Service users and carers should be involved in planning, providing and evaluating training for all health care professionals.

The important role that patients, particularly those with long-term health problems, can play in determining optimal care has also been recognised by the Government. In the White Paper, *Saving Lives: Our Healthier Nation*, the Government recognised the expertise that many patients have in relation to the management of their illness and "the importance of individuals making their own decisions about their health" (Department of Health, 1999*b*). Practical support for this policy has come with the setting up of the Expert Patients Task Force chaired by the Chief Medical Officer. The task force, which includes a user of mental health services, will look at the role of patients as experts in managing their illnesses and aims to set out the relationship between self-management and support from the NHS.

In this climate, discussion about whether or not users of psychiatric services should contribute to the development of psychiatric services or be involved in planning the care they receive has become redundant. Instead, the time has come to consider how potential problems regarding user participation can be overcome and plan areas where psychiatrists can work jointly with service users in order to address common concerns.

Service users as consumers of psychiatric care

Although not all patients expect, or want, to play an active role in planning their treatment, clinical experience suggests that a far greater number of patients will only engage with services on the basis that they are active participants in planning their treatment. Clinical practice and research evidence support the notion that users of psychiatric services are able to be actively involved in their own management (Bhui *et al*, 1998). Strategies such as self-help, psychoeducation and encouraging patients to identify early signs of relapse have all been

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†See pp. 87–88, this issue.

demonstrated to improve health outcomes. For an important minority of patients in contact with psychiatric services, a lack of capacity reduces their ability to play a full part in making decisions about care. An atmosphere of collaboration initiatives such as advocacy and advanced directives may allow greater involvement of these patients in decisions about the care they are offered.

Some psychiatrists have expressed concerns about users of psychiatric care contributing to the measurement of service outcome. Surveys of patient satisfaction have shown that clinical contact with psychiatrists is one of the aspects of care that users are least content with. Thomas *et al* (1996) argued that a possible explanation for this is that advances in biological psychiatry have led psychiatrists to conceptualise mental distress in a way that users of services find alien, resulting in psychiatrists being unable to “forge a genuine understanding of the patient’s concerns”. Such concerns emphasise the need for user involvement, particularly in training psychiatrists. Although there has been much discussion of this initiative (Crawford & Davies, 1998), it is now time for steps to be taken to ensure that user involvement is seen as a central element of the training process.

User involvement in planning services

The number of organised groups of service users has increased considerably over the past 30 years. Different groups take on different functions, including campaigning on mental health issues, providing advocacy to service users, formal involvement in the development of local services and providing alternative settings for supporting those experiencing mental health problems (Barnes & Shardlow, 1997). In order to facilitate the involvement of users in planning new services, the National Service Framework provides examples of good practice. These include projects such as ‘Northumberland User Voice’, where the local health authority funds full-time workers to facilitate service user involvement (further information about this service is available by e-mailing status@statusmeetings.co.uk).

Concerns are sometimes expressed about whether those who represent the views of service users do so accurately – how can one know whether or not the views of a service user reflect those of users more generally? This problem is not specific to those representing the views of service users. The same question could be asked of those representing the views of local general practitioners, psychiatrists, etc. Representatives of service users hold a range of opinions about issues such as the value of electroconvulsive therapy, in the same way that the views of psychiatrists and others also vary. Some user group representatives, such as mind link workers, are democratically elected. Others receive training that involves considering the distinctions between presenting one’s own views and those of others. Central to the concept of user involvement is the understanding that someone who has experienced services has developed an informed view that is of value to those developing and assessing services. Concern about the representativeness of service users must not be used to undermine the criticisms of service users.

Shared aims?

Increasing user involvement in planning and evaluating psychiatric services may enable an atmosphere of collaboration between providers and consumers of services to develop. Psychiatrists and service users share many of the same aims and concerns. In many areas staff shortages and outdated facilities mean that standards of care are far from ideal. In arguing the case for improving the availability of out of hours services or single-sex wards, the voice of health care professionals may be substantially strengthened by the support of local service users. Similarly, service users may be in a stronger position to pressure local health services to ensure that local psychiatrists are able to prescribe the most suitable medication, even if this requires further resources. Shared aims go beyond more money for services, and include developing services that are more effective. The success of several interventions in psychiatry is limited because of a reluctance of some patients to engage with treatment (Simon *et al*, 1993); and those who do not engage may have the greatest needs (Killaspy *et al*, 2000). Service users are ideally placed to contribute to the development of more acceptable services and need to inform research into new forms of service delivery.

Over the coming months the Government will be considering responses to the Green Paper, which will lead to new mental health legislation (Secretary of State for Health, 1999). It has come as a disappointment to many psychiatrists and service users that some of the suggestions made in the Richardson Report (Department of Health, 1999*c*) are not included in the Green Paper. The Green Paper avoids a commitment to advocacy, and appears to reject proposals for capacity-based legislation. Users and providers of services should come together to argue for these proposals to be included in any new legislation. These proposals seem more concerned with addressing public fears about risks posed by people who experience mental illness than with providing quality care for patients. At a time when the College is leading a campaign to inform the public about mental illness, working with service users in order to counter these fears has never been so important.

References

BARNES, M. & SHARDLOW, P. (1997) From passive recipient to active citizen: participation in mental health user groups. *Journal of Mental Health*, **6**, 289–300.

BRITISH MEDICAL ASSOCIATION SECRETARIAT (1994) *Core Values for the Medical Profession in the 21st Century.* Report of Conference held on 3–4 November, 1994 (ed. G. MacPherson). London: British Medical Association.

BHUI, K., AUBIN, A. & STRATHDEE, G. (1998) Making a reality of user involvement in community mental health services. *Psychiatric Bulletin*, **22**, 8–11.

CAMPBELL, P. (2000) The role of users of psychiatric services in service development – influence not power. *Psychiatric Bulletin*, **25**, 87–88.

CRAWFORD, M. & DAVIES, S. (1998) Involvement of users and carers in the training of psychiatrists: making it happen. *Psychiatric Bulletin*, **22**, 42–43.

— & KESSEL, A. S. (1999) Not listening to patients – the use and misuse of patient satisfaction studies. *International Journal of Social Psychiatry*, **45**, 1–6.

DEPARTMENT OF HEALTH (1989) *Working for Patients*. London: HMSO.

— (1999*a*) *A National Service Framework for Mental Health*. London: Department of Health.

— (1999*b*) *Saving Lives: Our Healthier Nation*. London: The Stationery Office.

— (1999*c*) *Report of the Expert Committee: Review of the Mental Health Act 1983*. London: The Stationery Office.

EASTMAN, N. (1999) Public Health psychiatry or crime prevention?: Government's proposals emphasise doctors' role as public protectors. *British Medical Journal*, **318**, 549–551.

KILLASPY, H., BANERJEE, S., KING, M., *et al* (2000) Prospective controlled study of psychiatric out-patient non-attendance. Characteristics and outcome. *British Journal of Psychiatry*, **176**, 160–165.

PFIFFERLING, J. H. (1980) A cultural prescription for medicocentrism. In *Relevance of Social Science for Medicine* (eds L. Eisenberg & A. Kleinman), pp. 197–122. Dordrecht: Reidel.

SECRETARY OF STATE FOR HEALTH (1999) *Reform of the Mental Health Act 1983: Proposals for Consultation*. London: The Stationery Office.

SIMON, G., VON KORFF, M., WAGNER, E., *et al* (1993) Patterns of antidepressant use in community practice. *General Hospital Psychiatry*, **15**, 399–408.

THOMAS, P., ROMME, M. & HAMELIJNCK, J. (1996) Psychiatry and the politics of the underclass. *British Journal of Psychiatry*, **169**, 401–404.

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