



opinion & debate

Psychiatric Bulletin (2001), 25, 87–88

PETER CAMPBELL

The role of users of psychiatric services in service development – influence not power[†]

Any review of service user involvement must acknowledge the progress that has been made in recent years. In the early 1980s service users were usually passive recipients of their own care and treatment and had little or no collective involvement, even in voluntary organisations that claimed to be speaking on their behalf. The few independent service user groups that existed were marginalised and lacked significant resources. In 1985 the House of Commons Social Services Select Committee Report on Community Care (1985) complained about the difficulty “of hearing the authentic voice of the ultimate consumers of community care”.

That complaint would be less credible now. Although legitimate concerns may still remain about what is the ‘authentic’ or ‘appropriate’ voice that people in authority should be listening to, few could now dispute that a much wider and more coherent range of voices are speaking out. Moreover, the debate surrounding service user involvement seems to have moved some way beyond arguments about whether service users have a right to be involved or have anything at all useful to contribute to issues about the how, when and where of involvement. When representatives of Survivors Speak Out first carried out a presentation at the Institute of Psychiatry in the mid 1980s, the conference spent the entire morning discussing who/what a ‘consumer of mental health services’ actually was. Nowadays, such preliminaries use up less energy. Service users who speak in public no longer spend the first 10 minutes of their time justifying their invitation. There is a real feeling that the circle around the camp fire has shifted slightly.

In the past 15 years activity by service users, as individuals, members of voluntary groups and in their own organisations, has been very diverse. While involvement with, and by, service providers in consultations over the planning, managing and monitoring of services – the government-approved features of involvement – has been at the centre of action, service users have also been involved in work where contact with mental health workers is limited or not directly to do with mental health services at all. As a result, it might be more helpful to think of service user involvement as an important element on a broad spectrum of service user action, rather than to claim it is the spectrum itself.

Service user involvement has individual and collective aspects. Increasing individuals’ control over their care and treatment is a fundamental goal that has been pursued with varying degrees of success. Following the introduction of the Care Programme Approach (CPA), there are now more opportunities for individuals to become involved in the process of making choices. Publications to assist people to ‘write their own careplans’ have been developed (Leader, 1995). The quality of their involvement and the effectiveness with which they put their case may be improved if they have access to an independent advocate. The amount of information that is made available to them about their care and treatment will have increased significantly. In some important respects the service user of today will be in a very different position to the mental patient of the 1960s and 1970s.

But these changes have limits. Increased involvement in the making of choices has not usually been matched by a greater range of choices. Although the CPA offers a framework of occasions at which service users can discuss their care and treatment, the process may prove arduous and unpleasant for them. There is some evidence that the resulting care plans do not always accurately reflect the service users’ contribution (Perkins & Fisher, 1996). Most significantly, there is a steady chorus of complaints about the amount of information that is available about treatments – surveys suggest this may affect 70% and upwards of those using psychiatric medications (Campbell *et al*, 1998). Whatever the rhetoric, the changes of the past 15 years have been in influence rather than in control.

The possibility that people with a mental illness diagnosis can make a contribution either to mental health services or to society is, historically speaking, a new idea. It is, therefore, not surprising that the collective involvement of service users has received a mixed reception. Their contribution of basic evidence about service use/consumption is now accepted as valuable and is reinforced by statutory requirements, although intermittent eruptions of concern about representativeness and ‘the professional user’ – a rarely defined derogatory term – suggest that some types of evidence are more acceptable than others. But when the focus moves from evidence to understanding and from service use to service provision,

[†]See pp. 84–86, this issue.



opinion & debate

training and research, the position becomes more ambiguous. On one hand professional organisations publicly encourage the greater involvement of service users (and carers) and acknowledge the legitimacy of direct experience, however, on the other there is resistance to non-expert views. In the same way that society is uncertain about the new population of patients living in their midst, many mental health workers are wary of those service users now involving themselves in mental health service development. Indeed, nurses and other professionals whose mental health problems become known, frequently encounter discrimination themselves.

The range of service user involvement makes global statements about success and failure very difficult. While there are clearly differences between the agendas of service users and service providers, service users and service user organisations often have different objectives too. The question 'what is involvement for?' might result in a number of answers. If improving the status of people with a mental illness diagnosis within the service system is one objective, then involvement might be seen as a moderate success. If changing the system itself is considered the aim, then it might be deemed a failure. Action by service users has not touched the clinical authority of mental health workers – an authority, the Green Paper (Secretary of State for Health, 1999) suggests, that will be reinforced in a new Mental Health Act. At the same time, the shape of services change extremely slowly. It has taken 15 years for service user demands for 24-hour crisis services to reach the top of the official provision wish-list.

After a decade and a half of service user involvement we have reached an important point in development without convincing research evidence as to whether involvement is working. Survey evidence regarding consultation and representation suggests a continuing concern about the quality of involvement, about tokenism and a lack of resources (Bowl, 1996). There is almost no research on how service user involvement in training mental health workers is developing, so that although there are good service user trainers available, it is difficult to grasp a sense of direction. Even advocacy, perhaps the clearest success story in recent years, does not seem to have assembled the relevant facts and figures, and is being snubbed by the Government as a consequence. Perhaps we have just not been taking this whole area seriously enough.

Most of the initiatives involving service users and service providers have been carried out under the banner of common interest. Working together, common concerns and partnership have been important words and phrases that have animated projects but helped conceal some of the realities – the different agendas and the imbalances in power. When the nature of service user and service provider relationships are critical issues, there must be some dangers in setting up such pre-emptive frameworks. When service users are always

invited but never invite, the true nature of partnership must be questioned.

It is, anyway, uncertain how long the rhetoric and practice of close cooperation can survive the change in Government priorities. At some level, partnership and compliance appear incompatible. The incorporation of people with a mental illness diagnosis into official language as 'nuisance' as well as 'consumer' is a significant shift that most groups of disabled people would find intolerable. Unsurprisingly, a number of local service user organisations involved in consultation have already complained that the viability of their work is being undermined by an atmosphere favouring custodial approaches. Although many service user groups depend on funding that is tied to providing the type of involvement that service providers require, it is more than possible that, by prioritising public safety over individual support, the Government will make consultation and representation less attractive and less practicable than it already is.

The great irony about service user action in the past 15 years is that, while the position of service users within services has undoubtedly improved, the position of service users in society has deteriorated. As a result, it is at least arguable that the focus of service user involvement needs adjustment. Service users and service providers should accept that the quality of life of people with a mental illness diagnosis in society, indeed their proper inclusion as citizens, depends on education and campaigning. Although the quality of mental health services will continue to be a dominant issue for service providers, it might no longer have such a place in the agendas of service user organisations. The climate may be changing – the Disability Rights Commission, the Human Rights Act, bioethics etc. We should not expect service user involvement not to change. Up to now it has been inward-looking and about initiatives with mental health workers. In the future it could look outwards and mean partnerships with people with physical disabilities, Black and ethnic minority groups and the poor.

References

- BOWL, R. (1996) Involving service users in mental health services: social services departments and the NHS and Community Care Act 1990. *Journal of Mental Health*, **5**, 287–303.
- CAMPBELL, P., COBB, A. & DARTON, K. (1998) *Psychiatric Drugs: Users' Experiences and Current Policy and Practice*. London: Mind.
- HOUSE OF COMMONS SOCIAL SERVICES COMMITTEE (1985) *Community Care with Special Reference to Adult Mentally Ill and Mentally Handicapped People*. London: HMSO.
- LEADER, A. (1995) *Direct Power: A Resource Pack for People Who Want to Develop Their Own Care Plans and Support Networks*. London: Brixton Community Sanctuary, Pavilion Publishing and Mind.
- PERKINS, R. & FISHER, N. (1996) Beyond mere existence: the audition of care plans. *Journal of Mental Health*, **5**, 275–286.
- SECRETARY OF STATE FOR HEALTH (1999) *Reform of The Mental Health Act 1983: Proposals for Consultation*. London: The Stationery Office.

Peter Campbell Service Recipient, 33 Lichfield Road, London NW2 2RG