being free and the latter funded by social services and means tested. Perhaps the conflict for the parent could be resolved by removing the means test until 16, while social services departments might be able to obtain central funding for this small group of children.

Not a comfortable option

Many will see this paper as a fundamental attack on the NHS, a means by which a free service slides down the slippery slope of privatisation. They will be ignoring the slide that has already taken place—and is accelerating. The structure that I have suggested is sufficiently robust to halt that slide and ensure that acute care remains free throughout. Long term care could develop, allowing the NHS to use the highest standards and train the staff required to run the private facilities. Patients and their carers would have a realistic choice freed from fears of favouritism and

unfair influence. Transfers to and from the private sector would be eased, enabling the NHS to concentrate its long term resources on those who need its special skills. Cynical health authorities would find the closure of long stay beds a less enticing option. Private homes would be free to compete on a more even playing field, no longer subject to the whims of the local health authority.

No one can pretend that this is a comfortable option. It does indeed make those who require nursing care through no fault of their own shoulder the cost. It does, however, remove the humbug which leaves the elderly to discover that our current free health service is a sham.

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3 *The hospital and health service year book*. London: Institute of Health Service Management, 1992.

Countdown to Community Care

Mental health services—the user's view

Peter Campbell

This is one of a series of articles looking at the forthcoming changes to community care

The needs of people with serious mental illnesses have dominated much of the debate on reforming community care. In this article Peter Campbell, who has used mental health services many times in the past, explains how the reforms could affect people like him. He welcomes the thinking behind the changes, particularly the idea that people who use community care should take part in planning services, but he warns that implementing the new philosophy might prove very difficult. Mr Campbell is secretary of a voluntary organisation for users of mental health services called Survivors Speak Out. The views he expresses here are his own, and do not necessarily reflect those of Survivors Speak Out.

The past three months have proved difficult times for community mental health care policy. As the starting date for the final and most substantial series of reforms approaches there are still major doubts and fears about the practicality and desirability of the changes. The much publicised case of Ben Silcock¹ and the health secretary's response to it² have once again revealed important differences among mental health care providers about which care is most necessary; it has also emphasised underlying uncertainties about whether community care for people with a diagnosis of severe mental illness can ever really work. A favourable consensus may still exist, but it carries a rather battered look.

In the face of such doubts a large number of mental health service users, including me, remain resolutely in favour of community care. We believe it is not only a viable option but the only option that can lead to significant changes in our status, as recipients of services and as citizens. We know that community care is no panacea and we share current anxieties that, without proper resources, institutionalisation may be replaced by neglect. But it is hard to see how the wider transformations we seek can be established except on the foundations that community mental health services could provide. In these circumstances our concerns are not that community care changes are a step too far, but that they will not go far enough to produce radical change.

Changing the location of care

It is certainly true that the location of care is changing. Community mental health care does imply the closure of the large, asylum style psychiatric hospitals, not least because many of the resources for new services are tied up in the old institutions. Closures have been taking place over the past 10 years. Soon the speed and scope of the closure programme will increase. A recent survey by the National Schizophrenia Fellowship has shown that 45 psychiatric hospitals will close by the year 2000.³

Hospital closures are major events in the lives of many users. As someone who has been admitted into psychiatric care 16 times in the past 25 years and has usually received acute care in asylum style settings, I shed few tears for the disappearance of these places. While I do not dismiss the care and treatment I have received during those admissions, I did not have to spend many weeks in the "old bins" to become aware of their shortcomings as therapeutic environments. The isolation—I have only once been in an admission ward less than a dozen miles from my home—and the physical environment—inappropriate design, upstairs dormitories that must be locked all day, uninvolved regimentation—are aspects of a system of care whose inadequacies should not be underestimated.

Moreover, while there are good reasons for concern about the availability of services for "revolving door patients" during the run down of the old psychiatric hospitals and while doubts remain over the capacity of district general hospital units to provide appropriate care to people in crisis, the relocation of the long stay population of psychiatric hospitals is achieving some successful results. There is evidence to support the anecdotal impression that long stay patients both prefer and are capable of living in community settings. Monitoring of people moved from Friern Hospital in north London and Claybury Hospital in Essex shows that they are not slipping out of the system and are enjoying a better quality of life with greater independence and a more varied social life.⁴ With adequate resourcing and well designed support systems, relocation can enhance lives.

But the community care reforms imply more than a shift in the location of care. According to the govern-

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You don't have to spend long in an old psychiatric hospital to be aware of the environment's shortcomings

JOHN TWINNING

ment's rhetoric, a fundamental change in the relationship between the provider and the recipient of care and treatment will transform the nature of services themselves. Thus the 1990 NHS and Community Care Act promises us a new approach to service provision that puts the needs of users and carers first. At the very least individuals will become consumers rather than recipients of care. At best their rights as equal citizens will be acknowledged and secured. While service providers are struggling to address "needs led assessment," "individualised care packages," and "care management" service users are beguiled with talk of "increased choice," "user involvement," and "patient empowerment." It is clear that something important is supposed to be happening. But what does it really mean? Behind the rhetoric, is the power of users, either as individuals or as an interest group, actually increasing?

Users are important

The role of users within the mental health system has developed rapidly over the past 10 years. Although the relation between the growth of action by organised groups of service users and the increasing importance of health service consumerism is not straightforward, the shift towards community care and the ideological changes accompanying it have undoubtedly given users the opportunity to become important stakeholders. In 1983, at the time of the introduction of the new Mental Health Act, seen then and now as a breakthrough for patients' rights, users were barely involved in the mental health debate. Users were also comparatively powerless within mental health voluntary organisations. Independent organisations of users were notable by their absence.

In 1993 there are more than 150 independent organisations of users in the United Kingdom. Major voluntary organisations like MIND and the National Schizophrenia Fellowship work alongside these groups, both locally and nationally, and have adapted

their own structures to represent users more effectively. The Community Care Support Force and the Mental Health Task Force—two recently established government initiatives—both have user representation. Up to half a dozen years ago any invitation by the government that offered users meaningful involvement in planning community care would have been seen as unrealistic and even cynical. In current circumstances such involvement is at least a genuine possibility.

Even so there are no grounds for easy optimism. All the evidence available points to the difficulty of involving users effectively in planning processes. Research on the involvement of disabled people in preparing local authorities' community care plans in April 1992 illustrates some of the barriers.⁵ Only one in eight local authorities had consulted disabled people before preparing a draft plan. No social services department had produced a plan accessible to people with learning difficulties. There was insufficient recognition that some of the voluntary organisations who helped with the plans do not adequately consult disabled people.

At the same time there are a series of practical problems affecting all consultation with users. Service users are rarely paid for their time. The conduct of meetings often excludes, alienates, or marginalises user representatives. The representativeness of service users' involvement is questioned far beyond that of other interest groups. Although the desire to involve users in planning and consultation is real enough, the unfriendliness of planning structures is not yet sufficiently recognised. Effective involvement in the future may depend not only on more extensive support for user representatives but on overhauling the planning process.

What users can do

It is possible that influencing purchasers of mental health services will prove the most direct way of changing services. In Newcastle a mental health consumer group has been working closely with purchasers over the past two years. The group participates at all stages of the process, including defining needs, revising draft contracts, monitoring existing services through visits or surveys, and contributing to planning future services. The group is already achieving some success, both in altering the detailed specifications in contracts and in challenging longer term mental health strategy. Considerable funding has been found to support the effective functioning of the Newcastle group. Perhaps purchasers or providers elsewhere would not be prepared to devote the necessary resources to involving service users in this way. Experience in Newcastle suggests it could be money well spent.

I believe it is unrealistic to expect the community care reforms to transform services according to the wishes of service users. There may be more room for choice in the new system and users may be in a stronger position to influence the planning of those choices, but the range of services is unlikely to widen. Notable differences remain between what user organisations are demanding and what service providers are willing to provide.

Despite 10 years of pressure for 24 hour, non-medical crisis services such facilities hardly exist in this country. In an era of choice and "needs driven" care, adequate support for people wishing to withdraw from major tranquillisers is not only absent but opposed. Funding restrictions may be partly responsible for these absences, but they also reflect the mental health system's capacity to resist new responses to mental distress. Community care will not circumvent this and will not automatically produce care and treatment that is any less reliant on medication as a therapeutic tool.

FRIERN HOSPITAL

People moved from Friern Hospital in north London are enjoying a better quality of life with greater independence and a more varied social life

These are not new issues; nor are they the only important issues for users. But there is a danger that the current reforms will leave untouched fundamental assumptions about the lives and needs of service users.

What will happen to users?

What about the individual users? Will their power increase even if the character of services remains substantially unchanged? Will they have more control over their own care and treatment?

The new arrangements should provide more occasions when mental health workers sit down with individuals to discuss their care in a structured way. The care programme approach introduced in April 1991 for people discharged from hospital and the individual needs assessments to be performed by care managers will permit greater involvement. But it is currently unclear how comprehensive these new procedures will be. A preliminary study by Research and Development for Psychiatry found that a quarter of health authorities had not implemented the care programme approach. In some districts it has been impossible to make it available to everyone. Care management is being introduced gradually and is focusing on those who are particularly vulnerable or need a wide range of services. Evidence from pilot projects shows the real potential of care management to create flexible care and support controlled by the user.⁶

Advocacy and representation

Real choices are informed choices, and the provision

of good independent advocacy and information services will be essential to the effectiveness of the reforms. Advocacy means representing and pursuing someone else's interests as if they were your own. The importance of advocacy in mental health services has been emphasised by the government and this has been reflected in a growth in advocacy projects such as patients' councils and schemes for individual advocates in hospitals. But advocacy services are not welcomed universally. They threaten change in the day to day practice of mental health workers and require a reframing of one to one relationships with clients. As a result it is perhaps not surprising that new advocacy schemes can be viewed with suspicion or seen as "troublemaking." Even where advocacy projects have been established, staff may feel that these are experimental embellishments to services rather than key elements of a new style of care.

In these circumstances the absence of full legal rights to advocacy and representation is particularly unfortunate. The government's refusal fully to implement the Disabled Person's (Services, Consultation and Representation) Act 1986 leaves users dependent on the good practice of service providers, without clear cut rights to assessment or explanation when services are not provided. Without a legal basis for users' role in the assessment process, without full rights to user representation, and without national minimum standards for community care, any increase in users' individual power may be illusory.

There is a danger of overestimating the impact of the community care reforms on the everyday lives of people with a diagnosis of mental illness. As consumers of a health and social care system, our range of choice and our control of our own care may be extended. But these gains will be limited. As citizens in the community, we may find no change at all. In the past few weeks the government has once again blocked an attempt to give disabled people legal protection against discrimination.⁷ The destructive poverty ruling the lives of people dependent on benefits is likely to continue and may grow worse. We may be becoming more visible. Will we be less marginal? The community care reforms have been linked with changes in attitudes within mental health services. Their significance to service users will depend on transferring such change to the wider society.

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5 Bewley C, Glendinning G. *Involving disabled people in community care planning*. York: Joseph Rowntree Foundation, 1992. (University of Manchester social care research findings No 27.)

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SUGGESTIONS TO AUTHORS

Hazlitt and T S Eliot advise on the choice of words

It is easy to affect a pompous style, to use a word twice as big as the thing you want to express; it is not so easy to pitch on the very word that exactly fits it. Out of eight or ten words, equally common, equally intelligible, with nearly equal pretensions, it is a matter of some nicety and discrimination to pick out the very one, the preferableness of which is scarcely perceptible, but decisive.

William Hazlitt (1778-1830), *On familiar style*.

And every phrase

And sentence that is right (where every word is at home,
Taking its place to support the others,
The word neither diffident nor ostentatious,
An easy commerce of the old and the new,
The common word exact without vulgarity,
The formal word precise but not pedantic,
The complete consort dancing together).

T S Eliot (1888-1965), *Little Gidding*, 1942.