Empowering the mental patient

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"The one who has the key has the power." That is how many patients in mental hospitals refer to the balance of power between patients and care-givers, particularly psychiatrists. It would be preferable if we could say "used to refer to", but unfortunately in some places the power imbalance still exists. However, the key is already being shared in other places.

Mental health services – like health services in general – have often been organized in relation to the needs of staff and of the services themselves. An important recent trend is the development of services built to respond to clients' needs and their problems in community living, rather than simply fitting mentally ill people into existing services.

But developing services around peoples’ needs is not an easy matter. First, you must determine their opinions and wishes. Second, reorganizing services to fit their opinions and wishes may mean major changes and may threaten vested interests. Third, there is as yet little firm and scientific evidence that the benefits arising from this new approach are superior to what went before.

WHO's Mental Health Programme sees the improvement of care for the mentally ill as one of its major tasks. Over the years it has promoted the provision of mental health care through primary and general health care rather than only through highly specialized services; it has reviewed legislation concerning mental illness, and issued guidelines about revising and drafting that legislation; and it has launched programmes on the prevention of mental and neurological illnesses, and developed guidelines about their treatment.

Removing the stigma

In the late 1980s it was clear that a major new challenge was to be faced: that of ensuring that care for the chronically mentally ill is given direct attention, and that its organization becomes based on a consensus among consumers, health service staff and the community. So the WHO Mental Health Programme launched an Initiative of Support to People Disabled by Mental Illness which is intended to facilitate the dissemination of information, to governments and to professionals, about good practice in community services for people with chronic mental illness, and about new developments in the field. The Initiative seeks to reduce the disabling effects of chronic mental illness and to highlight those social and environmental barriers which might hinder treatment and rehabilitation. These barriers prolong the stigma of chronic mental illness. The Initiative also advocates consumer empowerment and consumer evaluation of mental health services.

People who use mental health services have a right to be empowered, to have access to their own medical records, and to be free of stigmatizing labels.

The following are officially participating in the various activities:

- Mental Health Services (Northern Regional Health Authority) in Townsville, Australia;
- Mental Health Services (British Columbia Ministry of Health) in Vancouver, Canada;
- Centro Studi e Ricerche Salute Mentale (Autonomous Region of Friuli Venezia-Giulia) in Trieste, Italy;
- Mental Health Unit (Highland Health Board) in Inverness, United Kingdom;
- Ministry of Health, Netherlands.

In addition, several other groups in Austria, Finland, Germany, India, Japan, Russia, Spain, Switzerland, Uruguay, USA, and Zimbabwe have been involved in some of the Initiative’s activities.

The Initiative’s first step was to discover what the people who use mental health services – the consumers – think about them. These consumers included those with direct experience of mental or emotional problems, and also those who had some responsibility (e.g., as relatives or friends) in caring for mentally ill or disabled people. The views and approaches of several new consumer groups which have sprung up in many countries were incorporated into the Initiative’s activities, and this proved both fruitful and inspiring.
Consumer involvement

It was quickly apparent that consumer involvement in planning, development and evaluation of mental health services is necessary and useful; and that the prerequisites to an effective and equitable dialogue which will ensure consumers’ involvement in decisions affecting them include:

- the right to be empowered;
- the right to representation;
- the right to have access to one’s own medical records;
- the right to be free of stigmatizing labels.

Of these, empowerment was felt to be of particular importance. One consumer group from Vancouver, Canada, explained: “As the mental patients/former mental patients community is empowered, so must each individual in the group feel a sense of his or her own personal power. As in any context, it is the defenseless and the victimized who should be the facilitators of their own protection, dignity and respect. Therefore, participation in consumer groups should be exclusive to those who are or have been mental patients; only those who have suffered the stigma and the cold shoulder of the social fabric can truly claim an understanding of what their wishes and needs are.

While the exception can always disprove the rule, generally every instance in which there is equal participation, or significant participation, by non-mental patients in such a group, the non-mental patients always end up running the show. Control and power becomes centralized in the hands of the professionals and the so-called ‘normals’, so that within the confines of their own group psychiatric patients become once again disempowered.”

The approval by the United Nations General Assembly of Resolution 46/119 in December 1991, on the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, represents a major advance in line with the goals of the Initiative. Advocacy groups are now in a stronger position to put forward their views on consumer empowerment.

Faithful to its principles the Initiative has concentrated most of its efforts on identifying progressive services and groups that have emphasized consumer involvement; on networking with these services and groups; and on drawing attention to examples of effective interventions for the improvement of mental health care. One example: a booklet on Schizophrenia: information for families, produced with the collaboration of the World Schizophrenia Fellowship – a consumer association – is now being translated into some 15 languages.

A more recent project seeks to develop ways which will allow a more systematic examination of the degree of satisfaction that patients, relatives and formal care-givers derive from the services they use or provide.

Dr. José Manoel Bertolote, Senior Medical Officer, Division of Mental Health, 1211 Geneva 27, Switzerland, acknowledges the contribution to this article by participants in the Initiative of Support to People Disabled by Mental Illness.

Creative education for the mentally handicapped in Finland (above) and at the Townsville Centre (below).