

# Hearing *my* voice

**P**SYCHIATRIC understandings dominate our view of mental illness. This has not always been so. It was not until the mid-nineteenth century that psychiatrists wrested control of asylums away from lay administrators, before establishing their supremacy through the use of diagnosis and categorisation. Only after this were problems once seen as madness routinely characterised as mental illnesses. Although the 20th century saw challenges to medical pre-eminence, particularly through psychological and social approaches, it remains substantially unaltered.

Throughout these developments the views of people with a mental illness diagnosis have usually been invisible, to such an extent that many might have assumed they did not have any useful views and were intrinsically incapable of holding any. It is only in the last 30 years that it has become clear that those commonly described as mentally ill have important perspectives to communicate,



**PETER CAMPBELL** with a service-user's perspective on the impact of diagnosis.

and are more than capable of doing so.

The credibility of psychiatric diagnoses, particularly schizophrenia, has been criticised in recent years (Bentall, 1990). Challenges to the scientific concept of schizophrenia have never significantly involved mental health service users, who are generally more concerned with the consequences of diagnosis than the validity of the diagnostic process. Nevertheless, they are familiar with the transactions involved and frequently express anger about them. All diagnostic procedures are something of a mystery but psychiatric diagnosis, which relies so little on tests and so much on value judgements, is more

puzzling than most. Service users can be alienated by the questions professionals throw at them, questions that devalue areas of experience and fail to address their most pressing concerns. Clearly power is being exercised over them but how the evidence they provide leads to a diagnosis – and what impact that will then have – is not routinely explained. It is little wonder that the newly-diagnosed feel themselves to be victims rather than partners of the system.

Acquiring a diagnosis is frequently welcomed by individuals and their loved ones, particularly as it appears to define a problem and suggest that, under the leadership of appropriate experts, it can be

contained. A diagnosis can also facilitate entitlements like Incapacity Benefit or Disability Living Allowance or protection under the Disability Discrimination Act. On the other hand, there can be drawbacks. The central importance of psychiatric diagnosis to mental health services (you cannot be a long-term service user without one) leads to system responses that have a medical bias. Criticism of the medical model has been common among service user activists, partly because it does not deliver the types of services that service users want. The all-pervasive use of drug treatments that biomedical frameworks justify has been particularly criticised.

But the nature of care and treatment is not the only concern. Making sense of your life after the onset of severe mental health problems is crucial and has an important effect on whether you cope or go under. Barham and Hayward's (1995) study of the lives of long-term service users in a northern city shows very clearly the struggles people go through in coming to terms with their diagnosis. Individuals reported feeling trapped within a negative framework which (from a professional point of view) encourages the dismissal of significant, albeit unusual, aspects of their experience and (from a public perspective) seems to support stigmatising and discriminatory responses. There is no way that being known, or knowing yourself, as 'a schizophrenic' can be anything else than a heavy burden. After the cataclysm of entry into the mental health system, people with a mental illness diagnosis are trying to reorientate themselves. Unfortunately professional interventions frequently confuse them even further and end up pointing them in the wrong direction.

In recent years, alternative

understandings have begun to emerge from the grassroots. The voice of people with direct experience is now being heard: not just on the reality of using mental health services or living in society, but on the nature of mental illness itself. People who self-harm are speaking out about the inadequate and often punitive responses of Accident and Emergency services and suggesting that self-harm should be seen as a response to acute distress rather than attention-seeking (Pembroke, 1994). People who hear voices are challenging a medical concept central to a schizophrenia diagnosis and

developing new coping strategies (Romme & Escher, 1993). The importance of spirituality is being emphasised once more (Mental Health Foundation, 1999). In many ways the arrival of people with a mental illness diagnosis as 'experts by experience' has made the mental health field more interesting than it has been for half a century.

Psychologists need to be made aware of these new ideas. They also need to understand the reality of service users' lives. It is encouraging that service users are now involving themselves in the education of clinical psychologists. The availability of experienced trainers, whether freelance or members of local action groups, is increasing every year. Most of these will be providing sessional input and will not yet be involved in curriculum development, but it is still a sign of how far we have moved.

The presence of such experts in the educational field is challenging but rarely confrontational. While their meaningful involvement certainly demands extra time and energy from educators, there is now written material to guide good practice in this area (Tew *et al.*, 2004). Significantly, sessions run by service user trainers regularly receive excellent ratings in student evaluations.

Positive change in practice is more difficult to assess. Nevertheless, to a growing number of people, not least many service users, this feels like the way

forward. People with a mental illness diagnosis have been silent subjects of professional discourses for a very long time. The active presentation of their experience and understandings is a welcome change for the better.

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## References

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- Romme, M. & Escher, S. (1993). *Accepting voices*. London: Mind Publications.
- Tew, J., Gell, C. & Foster, S. (2004). *Learning from experience: Involving service users and carers in mental health education and training*. London: National Institute for Mental Health in England.

## WEBLINKS

Hearing Voices Network: [www.hearing-voices.org](http://www.hearing-voices.org)

Mental Health Foundation's Strategies for Living Project: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

National Self-Harm Network: [www.nshn.co.uk](http://www.nshn.co.uk)