

## Reading 2 Terms of engagement

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The users' movement in the UK has always been aware of the importance of language. We find terms like 'nutter' and 'psycho' degrading. We don't accept that psychiatric categories such as 'paranoid' and 'maniac' are scientific and value-neutral. There is much debate, as most readers of *Openmind* will doubtless know, about what we should call ourselves – users, clients, survivors. Wherever we stand, we know that language makes a difference.

Dictionaries supply 'definitions' of words in terms of other words. But 'meaning' is only found in context and the way language is used. Words and terms belonging to particular social groups and used in particular ways can be called 'discourses'. Some discourses are so dominant that they are taken as universal truths – medical discourse could be an example of this (though recent scandals such as the Alder Hey inquiry have challenged that dominance).

Professional discourse is a relatively modern phenomenon. It rests on a notion of 'expertise'. The French philosopher Michel Foucault has written about the development of the 'monologue of reason about madness'. By this he means that for centuries, first the priests and then the doctors have talked about, obsessed about, tried to explain and also practised upon the 'mad'. The subjects of this 'monologue' have not been allowed, by the very nature of the discourses, to make it a 'dialogue'.

Maybe that is changing. Let's take the category of 'mental illness' itself. Some service users think about their experience in illness terms. They have symptoms, they have an illness, they take medicine. Users who think about their experiences in the vocabularies and practices of psychiatry are not stupid or cultural dopes – they are not suffering from 'false consciousness'. They are making use of available, dominant discourses to understand and define their experience. And others are beginning to celebrate their experience through movements like Mad Pride.

People in the service user movement, are trying to construct alternative discourses. This process has some of its roots in the work of the 'anti-psychiatrists', such as R.D. Laing, who during the 1960s and 1970s reframed the 'irrational' as meaningful, even heroic. One of their legacies is seen in Marius Romme and Sandra Escher's idea that voice-hearers can construct their own 'narrative' in which hearing voices will be meaningful for the hearer. Similarly, sections of the user movement have substituted 'mental distress' for 'mental illness'. This is not just another word for the 'same thing' – it changes how we frame our experience.

Psychiatric practice has yet to find any real evidence of a physical reality behind mental distress. Its diagnoses are essentially social judgements. It follows that we need to interrogate its categories and find out just what values and associations go to make them up. But it is clear that the 'professional perspective' and the 'user perspective' are not equivalent or symmetrical. They stand to each other in a relation of power in which publicly authorised expertise has a dominant role to play.

In fact, no knowledge or language is value free or free of the social conditions of its production, however much it might claim to be a science or have an exclusive claim to 'truth'. The user/survivor movement too must be aware of its own ethical choices and social standpoints and be explicit about them.

## Research

If researchers want to find out what users think, it is very important to use the right language. Here is an example. It is an established finding that black users get very high doses of medication. One piece of research, which was oriented towards the rights of black users, asked them ‘do you think your medication dose is too high?’ Most of the users interviewed said ‘I don’t know, I don’t know what the right dose is.’ When service users themselves phrased a question about this, they asked ‘do you think you are overmedicated at all?’ This may seem like hair-splitting, but because the second question used the vocabulary of ordinary service users, the question was meaningful. In response to it, 30 per cent of those interviewed said ‘yes’ and only a handful said they did not know.

The recent report from the Sainsbury Centre for Mental Health, *Users’ Voices*, proceeds along these lines. We asked a series of questions about medication. By analysing the responses we were able to challenge one of the central themes of psychiatric discourse – compliance. This same process was applied to a whole range of mental health service issues, from the perspectives of over five hundred service users.

## Politics

We construct these new ways of speaking, these ‘emancipatory discourses’, by a painstaking process of deconstructing dominant ones. We borrow from the models of other groups in society – for example the social model of disability – and by using the discourse of rights. We produce a new common language of shared history. This is not an easy process, and it is far from finished. There is bound to be dissension. But we should not be worried about being ‘fragmented’ – emancipatory discourse has many sources.

We are all familiar with the use of psychiatric discourse to pathologise our protests – anger is a symptom, a complaint is a delusion. We need to argue back, not by simply re-stating our case, but by demonstrating that the psychiatric discourse is not coherent.

There has been a shift from the early days of the survivor movement to the contemporary focus on user involvement, at least at local level. The agenda of much ‘user involvement’ is set by the discourse of managerialism and policy-making. Local groups and their ‘representatives’ find themselves in the position of having to engage in consultation exercises on operational policies and business plans written by professionals. All that those involved can do when confronted with such documents is to propose amendments. They cannot challenge the premises on which such documents are based, or the terms in which the consultation is conducted, without pulling out of the involvement arena altogether. Some do exactly that. Others believe that a little influence is better than no power at all, and in this way, they find themselves committed to a politics of service ‘improvement’.

Also, because such involvement practices usually entail just one or two representatives sitting on a large committee, they have to behave themselves. Anger will not do in the way it did at earlier national conferences where there were large numbers of survivors who could support each other against charges of pathology. As I remember it, in the 1980s we wanted user-controlled alternatives to orthodoxy, not improvements to it. We were prepared to say so in no uncertain terms.

In the current situation, at least in some localities, survivors are no longer 'speaking out' from an alternative standpoint. The system is not being challenged by an emancipatory discourse. A positive identity as a survivor, forged through adversity, shared with others and able to understand others is not being offered. Mission statements nearly always say they want to promote the 'user voice'. They said that at the beginning of the movement and they say it today. But what that 'voice' amounts to has changed. In large measure, we have lost our rhetorical force and it has been replaced with a discourse of 'service improvement'. This is not to deny that there are radical discourses in play. Those that celebrate the positive side of madness, that see distress as something to learn from, or even see social change in prizing our wilder experiences – as Mad Pride – are an important counter to the new orthodoxy.

In trying to understand these processes, I hope we might yet recover the truly emancipatory voice of the users' movement.

## References

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