

## Perspectives

## 'Having a diagnosis is a qualification for the job'

I write this piece as someone with a diagnosis of bipolar affective disorder who, when in work, is also a researcher. I used to do research in education, gender, and media studies, but for the past two years I have coordinated the Service User Research Enterprise (SURE) at the Institute of Psychiatry, London. This is one of only two units in universities in Britain to employ service users and the only one where all employees have experienced mental health problems. The focus of SURE's work is on consumers' views on treatments and services, including treatments and services that I have received myself.

### Being "out"

It is not easy to admit to having mental health problems, and I have worked in research jobs where the associated stigma made it impossible to be frank. However, attempts at hiding my diagnosis and treatment were rarely successful. After a period of unemployment and positive contact with the service user movement, I decided that my best option was to seek research work within the mental health field. I would try to develop research methods that drew on my personal experience as well as my research expertise. This was nearly 10 years ago, when user focused research was in its infancy and drew bafflement, if not hostility, from those to whom we tried to explain it. But the situation has changed in recent times, and now user focused research is sought after, for the moment at least.

Moving (back) to an academic institution promised to be interesting. Colleagues and other service users spoke darkly of the "lion's den" and "being eaten for breakfast." This certainly did not happen, but there are tensions. Although our unit now comprises four people, there is still sometimes a feeling

of being singled out as the "safe user." Other service users, on the other hand, criticise us for being "co-opted," and I have sat uncomfortably in meetings being held to account for accepting a salary from the Institute of Psychiatry.

### The value of a double identity

So why do this? Because I think it can complement and sometimes challenge mainstream mental health research. Having received both inpatient and community care services for many years, I know how users experience these services. For example, a colleague and I recently conducted a review of consumers' perspectives on electroconvulsive therapy.<sup>1</sup> Both of us had undergone electroconvulsive therapy, and we were able to use our experience, along with other factors, to interpret the papers we reviewed. We found that studies reporting high levels of satisfaction generally interviewed patients soon after treatment, in the treating hospital, where the interviewer was the treating doctor, who asked brief and simple questions. We put ourselves in the shoes of these patients and suggested that many would want to please the doctor and would therefore not complain or would even express satisfaction so that the doctor would leave. We then combined this argument with statistical analyses of the studies.

This perspective should not compromise research rigour, and there may be a danger of being overinvolved. But I do not see this in our team any more than I see it in other professionals who are committed to their discipline.

### Drawbacks

Many user-researchers say that they get insufficient support. Now that there are four of us in SURE, we can offer each other sup-

port. However, it is also possible to have too much support. Those who supervise us in our jobs are mental health professionals, attuned to vagaries in people's feelings and behaviour. If a person becomes ill enough to take time off work, which I have done, managers can be too protective and not listen to an employee's own knowledge of his or her condition.

Among the many ways that power manifests itself in medical research is when senior academics do not treat a service user as a research collaborator, and simply regard the person as somebody's (a potential?) patient. I have been in research meetings that suddenly felt like a ward round. One's user status may be used to undermine one's opinions, as it is held that a person cannot be both logical and mad. It is a difficult balance to strike—that having a diagnosis and experience of services is a qualification for the job and not a handicap. This is the reverse side of the value of a double identity, and I do not pretend to have resolved the issue.

### Is it worth it?

It is certainly better than attending the day hospital every day. My conclusion is that it is definitely worth it, and I hope that will be shown by the research we produce. There is no doubt that it is emotionally draining. But if mental health research can take on board service users' perspectives, this, for me, will justify what we do.

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Competing interests: None declared.

<sup>1</sup> Rose D, Wykes T, Leese M, Bindman J, Fleischmann P. Consumers' perspectives on electroconvulsive therapy (ECT): systematic review. *BMJ* (in press).