



The experiences of mental health service users as mental health professionals

The Disability Discrimination Act 1995 has focused the attention of health and social care employers on the issue of discrimination within the workforce. This small exploratory study by Vivien Lindow and Susan Rooke-Matthews asked a range of mental health professionals, who have also used mental health services, about their experiences as members of this workforce and their recommendations for change. Interviews revealed:

- f* People working in mental health services who had received psychiatric or community mental health care reported discrimination from employers, colleagues and educators. This was true in both the statutory and the voluntary sectors.
- f* 'User employees' in the mental health workforce pointed to many positive ways in which their use of services added value to their work.
- f* Whether or not to be open about past mental health treatment was a central dilemma for user employees. This means that the existence of user employees remains a partly hidden resource among mental health workers.
- f* Job selection procedures are difficult for members of this group. In particular, it is often difficult for people to decide whether former use of mental health services will count for or against them in a job or training application.
- f* Initial professional mental health education as well as in-service training were described as discriminatory and difficult by students who have used mental health services.
- f* There is a low level of awareness of mental health equality issues by staff in the caring professions. A theme pervading the experience and recommendations of user employees was the need for all community care staff to have training in mental health that has a high input from service user trainers.

Experiences of discrimination

Interviewees who had received psychiatric or community mental health care reported discrimination from employers, colleagues and educators. This was true in both statutory and voluntary sectors. The minority of user employees interviewed who had been honest in training and at work about their use of mental health services felt that:

- they were devalued and treated as more vulnerable than their colleagues, and subjected to increased surveillance;
- their working behaviour was interpreted in a way that emphasised their vulnerability or difference, and they had to work harder than their colleagues in order to be taken seriously;
- complaints they made about working conditions or aspects of the service were seen as 'symptoms' or attributed to their own distress;
- they were accused of crossing professional boundaries and/or over-identifying with clients and patients, promotion did not seem to come their way and they were sometimes subjected to other direct and open prejudice.

"I think that people who don't actually have a lot of knowledge of mental health problems, bring to people who say that they've had a particular problem a load of preconceptions ... it's not only about you as a person but about your ability to be an effective worker. Well, I think it helps me be a more effective worker, but I suspect that wouldn't be a management view."

Many user employees felt that even when employers and colleagues stated a lack of discrimination against users of their services, in practice there was widespread institutional discrimination that was not recognised.

The value of experience

Many user employees were convinced that their experiences were of value in their work. User employees felt they had additional understanding of service users' lives and experiences of discrimination.

"It exploded my own stereotypes and made my issues a lot less threatening. I think I became very aware of how much people retreat from you if you've been mentally ill."

People did not expect to be employed only on the grounds of having used mental health services. They did expect to have an equal chance in selection procedures and to have any added value gained from their experiences of mental distress respected by colleagues and employers. User employees felt they could be a positive model.

"If it was safe enough to be 'out' about it, I could be a model of, that it's possible to go through a lot of distress and come out with a lot of joy and creativity and things in my life, and function pretty well."

They could also have an immediate understanding of some experiences of trauma or unusual behaviour.

"I have some understanding of the rationality inside what somebody is seeing as bizarre behaviour and different states of consciousness and things. I think I have an understanding of the amount of pain that could be involved in being distressed and disturbed. I mean, to me, I couldn't believe the amount of mental pain that I went through."

User employees were likely to have more positive attitudes:

"I know what it feels to be in the pit of nothingness and yet be able to move out of it and know it goes away. And I think that helps me to look at the situation of the person that I'm working with. To think about how they could move on from there. And also to say that it is possible to move on with some certainty."

People who had received services after becoming workers often found that the experience had changed their practice for the better:

"I don't think I had the slightest understanding about what it was like for them, not a clue. I was very good on the kind of academic theory ... but in terms of the way I worked with clients I actually shudder now. I learned so much very quickly from my fellow patients, things that I'd never really understood or even had any conscious thought about as a professional."

User workers could also give a valuable perspective to fellow workers:

"I think I can offer a resource for research. You know, in all my history with the system as a patient I don't think anybody ever said 'What does it feel like?'"

To lie or not to lie?

Until recently, someone seeking work was almost certain not to get it if they disclosed use of mental health services. Whether or not to disclose past (or current) psychiatric treatment remains a central dilemma for user employees.

"One of the things I've always had to do is keep it a secret because if you don't keep it a secret you're considered to be unworthy of the job or inadequate or a failure or whatever. So I've always kept it a secret."

"I believe in being quite open about it anyway ... well I mean, I couldn't live with the knowledge that I would be found out some day or not. Apart from the fact that a person should be assessed on their ability to do the job not on what's happened in the past."

Most people did not want to lie, but felt they must:

"It feels an enforced deception. I don't want to do this, I want to share with people when appropriate but I don't feel as if I can because I've also got a career."

Some people made a stand, and did not lie:

"We let people discriminate against us because we hide it ... You can't live with a lie, you've got to have an awful good memory. And also, I mean, at that time, I used to think, 'well, what happens if I get ill?' ... I half expected it all of a sudden at that stage. And I never lied about it."

Some user employees waited until they were settled in a job and seen to be competent before revealing their use of mental health services.

"I still find myself really nervous about saying 'I have a psychiatric history' because ... I never know whether to tell or not to tell and how it's going to be received. And what I always do is I wait 'til I sort of prove myself and people sort of say, you know, 'you're a really good clinician' ... and then I say, 'Well, I have got experience of it myself'. And I don't think I'd ever go in cold and say, 'I'm an ex-psychiatric patient, employ me'."

Few advertisements for posts in mental health services state that employers welcome applications from people who have used mental health services. Sometimes an application form has a section explicitly asking about personal experience of mental health services.

"It's not a problem that anyone else can solve as to what you put on an application form. Or the implications if you say 'no' when you do have problems, and if you say 'yes', well they won't have you anyway. So I'm acutely aware of this and that has actually stopped me from applying for several jobs."

User employees were often uncertain whether such a question was included to filter candidates out unless positive statements about former mental health service use were made.

"They did say on the application, I think, 'we would prefer' you know 'people with mental, who've experienced mental health problems'. And I just, it was a very unconventional application form anyway, and I thought, well I've got nothing to lose, I can only be honest about myself and my own experiences ... And so I was honest and I applied and I got the job."

People were clear that they did not want to be accepted for interview or appointed simply because they have used services. They did want the opportunity to be honest in their application and judged equally with other candidates.

Implications for better practice

Interviewees suggested the following:

Recruitment

- Involve service users in selection procedures.
- Offset interrupted work history by accepting such experiences as volunteer work and membership of self-help organisations as relevant to the application.
- Take care not to request non-essential qualifications.
- Avoid setting up difficult interview situations which may have no bearing on job performance, such as giving a presentation.
- Give opportunities to discuss people's experience of mental health services and what advantages or disadvantages this might have for their work.

Work arrangements

- Modify the workplace to give some privacy or space with minimum distractions.
- Encourage support groups for workers.
- Facilitate access to professional counselling if needed.
- Create flexible work schedules.
- Give time off during the day or allow people to leave early when stressed.
- Authorise leave for periods of distress.
- Permit 'at home' working.
- Allow exchange of duties with another employee.
- Encourage a climate of extra tolerance for unusual behaviours.
- Have guidelines for providing negative feedback.
- Look at creating a scheme for on the job peer counselling.

During sick leave

Examples of helpful behaviour described included:

- Colleagues and immediate managers offering support and keeping in touch.
- Giving information about the person's legal employment position.
- Colleagues making it clear that if the person is seen 'out and about', this does not mean that they are expected back at work until they are ready.
- Being able to call in at work and receive a friendly reception.
- Being able to make a 'therapeutic return' in which the person is paid in full but works fewer hours than usual.

Difficult issues included:

- The enormous power wielded by the psychiatrist in relation to returning to work and other aspects of current and future employment.
- Being admitted to a ward where the worker is a colleague, without discussion.
- Confusion about boundaries from ward staff.
- Confusion about boundaries from work colleagues.
- Direct prejudice from mental health workers.

Professional training

Interviewees felt teachers should:

- Have a clear and open policy on what students with personal experience of the psychiatric system might have to offer and the support they might need to function at their best.
- Not assume that students who are survivors will necessarily need more support than other students.
- Think through the course 'party line' on issues like professionalism, boundaries and personal disclosure.
- See survivor students as a resource, but not the only resource, on mental health issues.
- Introduce training in mental health for all students on more general courses, such as social work or occupational therapy.
- Make sure that all training has more than token input from service users in curriculum development and in presentation

Difficult issues included:

- Issues of identity, particularly connected with moving from being a service user to being a worker.
- Training material that stimulated memories and past feelings.
- Being sent on placement where they had been service users.
- Needing to be particularly aware of issues such as self-disclosure when working with people who in another situation might be their peers.
- Being faced with prejudice from staff and other students which they did not feel able to confront directly.
- Being presented with an image of mental distress which emphasises the medical aspects, has low expectations of service users and lowers their own self-esteem.
- The fear of service use being discovered if they went through a difficult patch or were using mental health services while a student.

Awareness of mental health equality issues

To counter the low level of awareness of mental health equality issues interviewees suggested:

- All mental health staff need to have in-service training that has a high input from user trainers.
- Service users should specifically be included in the organisations' equal opportunities policies and procedures.
- Staff/management workshops allow staff at all levels to examine their attitudes to mental health issues, to users of their services and to colleagues who have used mental health services.

About the study

The 36 informants in this small qualitative study were social workers, mental health nurses and other workers in statutory and voluntary sector mental health services. Each person was interviewed separately, and some of these attended a day workshop which produced many of the ideas included here.

This work was part of the project Mental Health Service Users as Community Care Providers project, undertaken from the Social Work Department of Bristol University.

How to get further information

A fuller report, *A survivor's guide to working in mental health services* by Susan Rooke-Matthews and Vivien Lindow, is available from Mind Publications, 15-19 Broadway, London E15 4BQ, Tel: 0181 519 2122 (price £2.50 plus 25p p&p). The researchers can be contacted at 8 Oak Road, Bristol BS7 8RY, Tel: 0117 942 5278.

The following *Findings* look at related issues:

- Housing and mental health care needs of Asian people, Jan 96 (*SC79*)
- Accommodation for older people with mental health problems, May 96 (*SC87*)
- Involving users and carers in the care programme approach in mental health, Oct 97 (*SC97*)

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