

VIEWS AND EXPERIENCES OF EMPLOYMENT AMONG PEOPLE WITH PSYCHOSIS: A QUALITATIVE DESCRIPTIVE STUDY

STEVEN MARWAHA & SONIA JOHNSON

ABSTRACT

Background: Work is important for mental health but we are only just beginning to understand why so few people with psychosis in the UK work.

Aims: To identify the opinions of a purposive sample of patients with psychosis on themes related to employment.

Method: A thematic analysis of 15 semi-structured interviews with people with schizophrenia or bipolar affective disorder.

Results: Participants identified a range of advantages to working but also expressed substantial doubts. Symptoms, medication and potential damage to health are the problems that people believe affect their ability to work. Most people would not tell their employers about their illness because they feared discrimination during the selection process, but believed it could help their chances of retaining a job if employers knew. A number reported a lack of encouragement to work from mental health professionals and not enough helpful employment services.

Conclusions: Although most people want to work, given the pressures they face some may choose not to. Barriers that people face are both internal and external and these interact.

BACKGROUND

Unemployment is known to be harmful to the health of the general population (Bartley, 1994) as well as being an element of the social exclusion that those with severe mental illness (SMI) face. Health and social services in the UK have a responsibility to lessen this exclusion and reduce discrimination and a requirement to consider employment in the care plans of those with SMI (Department of Health, 1999). The economic cost of unemployment among the mentally ill is high, both to the state and the individuals concerned (Boardman, 2003a; Huxley & Thornicroft, 2003). There is a distinction between employment and work. Work is 'essentially something you do for other people' whereas employment 'is work you get paid for' (Boardman, 2003b). Among the long term disabled, people with SMI find it more difficult to get employment than those with physical disabilities and it is only those with severe learning disabilities that are less likely to be in paid work (Boardman, 2003b; Social Exclusion Unit, 2003).

The vast majority of people with mental illness say they want to work (Secker *et al.*, 2001; Hatfield *et al.*, 1992) and would like to do jobs that those without psychological problems also do (Shepherd *et al.*, 1994). Employment in people with SMI has positive effects in terms of quality of life and self esteem (Van Dongen, 1996) and there is a correlation with a greater satisfaction with life (Priebe *et al.* 1998). It has also been suggested that employment is associated with a reduction of symptoms and the number of times people are admitted into hospital (Bell *et al.*, 1996; Reker & Eikelmann 1997).

Despite the social and economic benefits of employment and its possible effects on health, only 8–20% of people with a psychotic disorder in the UK (Kelly *et al.*, 1998; UK700 Group, 1999) and 15–25% in the US (Lehman, 1995; Ridgeway & Rapp, 1998) are currently employed. Furthermore this figure may be falling (Jeffreys *et al.*, 1997; Perkins & Rinaldi, 2002; Marwaha & Johnson, 2004). We are only just beginning to understand why so few people with psychosis work. Suggestions include that service users are concerned that work may be stressful (Van Dongen, 1996) and may therefore lead to a relapse of their mental illness. Concern over the loss of disability payments if people work is likely to be important (Polak & Warner, 1996; Rinaldi & Hill, 2000). Given that a sizeable proportion of the general public interviewed in a recent survey believed people with schizophrenia were dangerous and difficult to talk to (Crisp *et al.*, 2000) stigma and discrimination from employers (Manning & White, 1995) may be a potent barrier.

The experiences of service users with SMI in trying to obtain and keeping employment and the perceived barriers to working have been the focus of only a limited number of investigations. Studies carried out to date have usually used questionnaires to assess attitudes and experiences and this is unlikely to capture the full complexity of participants' views and experiences related to work. In addition many studies have interviewed people with a variety of psychiatric diagnoses. People with SMI have lower employment rates and poorer occupational outcomes than those with other psychiatric problems (Gureje *et al.*, 2002; Bland *et al.*, 1988) and may therefore have different experiences and opinions.

AIMS

This study aimed to identify the views and experiences of a purposive sample of fifteen patients with SMI on the following themes:

The advantages and disadvantages of working from service users' perspectives.

The ways in which illness affects the ability to work.

Experiences of looking for work and perceived barriers to finding and keeping it.

Opinions on current service provision.

METHOD

A qualitative method, based on thematic analysis of transcripts from semi-structured interviews, was selected in order to allow detailed exploration of participants' views and experiences

and to avoid imposing a fixed set of categories on a complex area in which only very limited previous evidence is available.

Sampling frame

Approval was obtained from the local research ethics committee. For the purposes of the study, SMI was operationalised as an established diagnosis of schizophrenia, schizoaffective disorder or bipolar affective disorder, a somewhat narrower definition than often used. Four care co-ordinators in a community mental health team (CMHT) were asked to identify patients on their caseload who met these diagnostic criteria and were not in hospital. A total of 52 names were provided and consecutively numbered 1–52 to code their identity.

A purposive sampling method was used in order to ensure that a full range of service user characteristics and experiences was represented. Thus before recruitment we determined that the sample should include at least six males and six females, at least five unemployed participants and at least 5 who were currently employed (including competitive and voluntary employment). In addition at least six people with schizophrenia and six with bipolar affective disorder (BPAD) were to be selected. People with psychotic depression were excluded as previous research (Bacani-Oropilla *et al.*, 1991) suggests that this group have different employment functioning to those with schizophrenia and BPAD. Participants were selected from groups of patients with particular characteristics (for example, diagnosis of schizophrenia, employed). If a potential participant refused to take part in the study, another was recruited until the required number had been interviewed. Given the high level of morbidity required for key-worker allocation in inner city CMHTs, only a very small number were employed in the initial participant list. A further five participants who were employed were therefore recruited from the out patient list of the CMHT.

Potential participants were initially contacted by phone, told about the study and asked if they would be willing to meet SM to discuss it further. If a telephone number was not available or they were not contactable by phone a letter was sent to them requesting participation.

The interview

SM and an occupational therapist developed the qualitative interview guide with the study aims in mind. To assess face validity and refine the interview it was piloted with three potential participants from the patient list of the CMHT. These people were unemployed, applying for a job and employed in a voluntary capacity.

Participants were told that responses were confidential and their identity would be concealed in the final analysis. The interview schedule was used for exploration as a starting point but the respondents determined interview content (design flexibility), allowing them to introduce relevant themes not included in the initial interview guide. Our primary interest was in exploring views and experiences related to paid employment, but the scope of participants' responses often included discussion of work as defined more broadly rather than only paid employment. The interviews were recorded on audio-tape and transcribed by secretarial support staff. A sample of the transcripts were compared to the recordings on tape by SM and found to be accurate. An outline of the final semi-structured interview used is shown in Appendix 1.

Demographic and clinical details collected included age, gender, diagnosis, current employment status and previous work record (work pre and post-illness onset). One interview was carried out in the person's home and all the others at a community mental health centre.

Analysis

Thematic analysis of the transcripts of the interviews was carried out using QSR-NUD-ist Classic (a programme which supports qualitative data coding and analysis) to identify beliefs, attitudes and experiences. SM initially read and coded all of the transcripts for the demographic details described above. Further reading of the interviews enabled a coding structure to be developed, with the questions asked during the interview as a starting point. In this way text within the transcripts was coded into themes. Novel ideas not specifically asked about in the interview were also identified and assigned codes. The text within each code was then re-read to check for the validity of the coding and to see if further themes could be identified.

Validity and reliability

SJ independently coded four randomly selected transcripts to check the validity and reliability of the coding structure. However the level of text coding agreement between SM and SJ was found to be less than 75%. In response to this, the definitions of some of the themes were refined and the coding framework was further developed by the addition of new themes. All the transcripts were then re-coded using the new coding framework. SJ independently coded two further transcripts to recheck coding reliability. This was found to be satisfactory at 80%. The main remaining discrepancies were text-coding omissions as opposed to text coding differences.

The setting of the study

This study was carried out in Islington, North London, an area with considerable deprivation, a population of approximately 176,000 and an unemployment rate of 9.1% (OPCS, 2001). Local specialist employment services for people with mental illness are limited and are mainly provided by the voluntary sector. Available services include the Employment Project (provided by a national voluntary sector organisation which campaigns for and provides services for the mentally ill), which assesses work skills and provides training on how to get work. There is also a day centre, which provides some vocational rehabilitation. Sheltered employment is limited and there is no substantial scheme providing supported placements in competitive employment. There is a high quality benefits advice service (Islington People's Rights).

RESULTS

The socio-demographic details of the final sample are shown in Table 1. Everyone in the sample had done some form of work in his or her life. Nine people selected did not participate. Two of these were uncontactable and seven refused.

In describing the results we have at times reported the number of interviews in which a particular theme was identified. This is intended to illustrate the relative prominence of themes in

Table 1
Socio-demographic details of participants

Characteristic	Number of participants (N = 15)
Gender	
Men	8
Women	7
Diagnosis	
Schizophrenia	8
Bipolar Affective Disorder	7
Age	
18–40 years	9
Over 40	6
Ethnicity	
White UK	10
Greek	1
Italian	1
Turkish	1
Black African	1
Argentinean	1
Employment status	
Unemployed	8
Competitive employment	3
Voluntary or sheltered employment	4
Worked pre-illness and post-illness onset	14

this sample: these figures cannot be equated with frequencies reported from a statistically representative group of people with SMI.

Desirability of working

Nearly all of the interviewees (13 out of 15) said that they wanted to work. Two of the participants, both of whom had schizophrenia, felt they could not work because they were not well enough. One of these said: '*I would like to work if I didn't have mental health problems. I have a lot of insurmountable mental health problems that get in the way*'.

Although people almost always said they wished to work, many (six) wished to work only part-time as they felt they could not cope with starting full-time work directly from unemployment. An unemployed man with schizophrenia said: '*I would prefer to do part time jobs for a few years to see if I can handle that. It's a lot easier to do*'. When asked why, he said, '*basically to see the stress levels aren't too high*'. However, some respondents reported that they would not consider part-time work because the pay would not be enough given the loss of benefit entitlement.

The participants gave a number of reasons why working would be advantageous to them. The commonest was financial gain. This was not solely related to the desire to be wealthier but also to increasing a sense of autonomy and independence by ceasing to rely on benefits. Participants believed it would give them more control over their lives. For example an employed woman with BPAD said '*the advantage for me in work is the sense of self-esteem, the fact that I would be earning my own money, making decisions about my life*'. Participants

talked about work giving them a clear role and empowering them to become part of mainstream society once again. For example, a man with schizophrenia said, '*it would certainly help to give me more of a purpose to life. On the mental health scene if all you do is visit day centres, it means you're just drifting. It's not like having a career or a job*'.

Four participants, three of whom were employed, said that working was good for their mental health. An older employed man said, '*I mean I'd hazard that yes, it's extremely stabilising. It's a form of creative Lithium if you like*'. There were no other obvious differences by employment status. Other advantages of work cited were opportunities to meet other people and provision of daytime structure.

After the initial strong assurances of wanting to work and its advantages, many participants went on to express substantial doubts. These ranged from a fear of letting people down to doubts about physical ability to work. Concern about benefit entitlements if they were working was common in the sample (7), but less so among the employed (2/7). A woman with BPAD said: '*I think the benefit system does work against people with mental health problems actually getting back to work*'. There seemed to be a good deal of uncertainty about how much money one could earn and the relationship between earnings and loss of benefits and many people believed that they would almost certainly lose their benefits if they did any paid work, even if this was as little as a few hours a week.

A number of people expressed their concern over whether in reality they would be financially better off and seemed to be well aware of the 'benefits trap'. An unemployed man with schizophrenia said, '*I don't think it would make a lot of difference. I'd have to pay council tax and I'd have to pay fares. I don't think I would be better off financially. I mean people just say I should work but they don't think of the consequences*'. The minimum additional payment that people were willing to work for was £50 a week more than their current benefit entitlement.

The nature of the work that they might be required to do also seemed important and a few participants, often those whose level of social functioning appeared generally high, expressed reservations about having to work in an unskilled or unsatisfying job. For example a woman with BPAD said, '*something that was interesting, of value, that I felt appreciated in. I mean basically I'm pretty sure I could get a job stacking shelves in Safeway or whatever but I don't want to do that*'. Some respondents suggested they had found alternative activities from which they gained some of the satisfaction they might get from work. For example, a woman with BPAD said: '*I consider I'm already working. I'm a mother, I've been engaged in promoting good practices in mental health, I'm a regular member of the day centre so I'm constantly engaged in doing things*'.

Mental health problems and effects on work

When asked how their mental health problems might affect their ability to work most participants (12) said that symptoms of their mental illness, primarily affective or psychotic ones, would interfere with functioning at work. A woman with schizophrenia said, '*the voices . . . lack of concentration*'. She went on to say '*I need help with the voices. It would help if I didn't hear them anymore*'. Two participants also thought concentration or memory problems would affect their ability to function at work.

Taking medication and working was seen as problematic by many participants because of side effects (6) or the practicalities of administering it (2). An unemployed man with schizophrenia said '*now I have to have an injection every two weeks. Do you tell your prospective*

employer that you suffer from mental illness and that you want time off to go have your injection or do you make some excuse every time? It's a bit of a quandary really. A minority (4) talked about problems getting up in the morning making it difficult to work.

Concern that working might lead to a relapse of their mental illness was very common (five unemployed and four employed). A few had experienced this while others saw it as a risk. A typical comment was '*could be stressful job and I won't be able to cope with it and I'd end up having another breakdown*'. Many talked about their experiences whilst at work and how their mental health problems had affected these. An unemployed woman with schizophrenia said '*my face is always red, I look very anxious. I used to work in a shop and realised I looked very anxious, so I stopped working in the shop*'. A man with BPAD said, '*. . . other times I've probably gone over the top in (work). I remember writing down dozens and dozens of comments, overflowin'*. When asked if his employers were supportive he said '*I just left and gave up my job . . . and that damaged my career irreparably*'.

When people had stopped work due to their illness they had nearly always left of their own accord rather than being dismissed. This had often happened at a time when their illness was becoming worse but they did not feel able to talk openly to their employers about it. They either resigned or simply did not turn up for work because of behavioural disturbance or being admitted to hospital. In a typical comment an unemployed woman with schizophrenia said '*Well that is why I left telecoms, because I walked . . . Well I thought people were talking about me and then things started going fast in my head*'.

However, pressure from employers and colleagues may have contributed to these decisions to leave work. A number of people described feeling discriminated against at work when they became ill, and also on their return to work. It appeared that this was often disguised; for example being asked to move to an area which was not so easy to commute to or being asked to take a demotion. A man with BPAD who took medical retirement when he returned to work after a manic episode said '*well what happened was, I went back and I felt a bit ostracised. People weren't as friendly as they were before. I don't know why*'. Only three participants had been sacked. This was because their employers believed they could not do the job any longer due to their mental health problems. An unemployed woman with schizophrenia said '*after I went into hospital, I started again and then they said I must not work in this place . . . I get tired very quickly and nobody helped me . . . I started making simple mistakes. Before I never done these things*'.

Despite these problems several people described instances of obtaining work or keeping a job despite illness. Participants frequently talked about their employers knowing about their mental health problems and therefore providing them with support at work as the key to enabling them to continue. For example, a 24-year-old employed man with schizophrenia said '*and they said that if it didn't increase (work-rate) they wouldn't be extending my application for a full-time position. But I told her about my schizophrenia and afterwards she said, well I'll scrub off the statement about not keeping you on, but if you can make those improvements*'.

Attitudes to employers and the perceived beliefs of employers

Stigma was frequently discussed when people talked about their prospects of finding work. Approximately two thirds of the participants said they wouldn't tell potential employers about their mental health problems because they feared discrimination. A 35-year-old man

with schizophrenia said, '*I don't think you'd get a foot in through the door that way. You wouldn't get taken on in the first place if you told them you had a big mental history.*'

Even though most people would not tell a potential employer about their mental health problem, about a third thought their situation would be better if the employer were aware of and accepted it. This belief co-existed with believing it to be important to hide mental health problems from the employer initially so as to get work. For example, when asked if he would disclose his illness during the selection process a man with schizophrenia said '*Not if I wanted the job but then that would increase my likelihood of going nuts, because I wouldn't let anyone get too close or meet my friends who did know I have a mental health problem.*' The most commonly cited reason for telling an employer was so that they would be forewarned that the person might become ill and that this might affect their performance at the job.

The belief that employers would prefer not to employ people with mental health problems was almost universal. Most people (11) believed that employers would worry about their functional ability to do the job as well as about risks. A 35-year-old man with schizophrenia said '*it's a risk to the employer and they might go mad one day with a big knife and attack someone. Or they might just not be as efficient as someone who hasn't got mental health problems.*' Participants thought that as well as the risk of violence, employers would be concerned about the number of sick days taken and disruption to the work force. The three people who were competitively employed had not told their employers about their illness at the interview.

Interestingly, a significant minority of participants (6) thought that employers were justified in their concerns and reluctance to employ people with SMI. A young man with schizophrenia who was employed commented '*just say there's two different people. One with mental problems and one's fine. The one who's fine can be told I need you to stack four shelves today . . . whereas this one he can do it but he still needs support . . . I think he'd be a bit of a burden on the employers.*' Some participants had self-stigmatising views of those with SMI with regards to work. A woman with BPAD said '*in all seriousness I'm not sure unless you had a vacancy you couldn't fill you'd take on someone with mental health problems anyway.*'

Getting a job

Only a minority of participants was currently actively seeking employment. Seven participants talked about advice regarding work received from professionals or the lack of it. Those over 40 years of age seemed more likely to have been advised against working or against more demanding employment. In talking about her struggles to lead a normal life a woman with BPAD reported '*one psychiatrist told me I'd only ever do menial work, that I'd never be fit to do anything that required responsibility. I named her Dr Murderoch.*' Two participants under 40 years said that no one had mentioned work to them or explained what services were available.

When asked how they might go about finding a job, people mentioned three strategies: attending the local Employment Project, trying to find work themselves by looking through adverts or going to the job centre (government run centres open to all in which jobs are advertised and help and advice regarding job hunting and making a claim for benefit is provided). The latter was perceived as the least effective option. For example an unemployed woman with BPAD said '*I think they'd push me into a job that I didn't think I'd be able to do . . . I find going to the job centre the most soul-destroying experience. Then again everyone would.*'

The people who used the Employment Project found the service friendly although generally unsuccessful in helping them to obtain competitive employment.

The majority of participants had done some form of voluntary work in their lives. Many of them discussed this type of work positively as increasing their self-esteem and providing an environment where they felt supported and could work despite their mental health problems. However, a few people said that they would never do voluntary work because of the lack of financial remuneration. The majority believed that voluntary work did not prepare you for competitive employment. A man with BPAD described the positive aspects and problems with voluntary work: '*I just saw it as voluntary work, I didn't really see it as preparation for a full-time job. The discipline of getting up in the morning is a good idea . . . but all other aspects doesn't . . . because you can do what you like, you can either work or you don't*'.

Most thought that not enough specialist employment services were currently available. People identified a range of functions that a dedicated service might serve. These included help with filling out application forms and curriculum vitae, support and advice on interview skills, and the provision of references. Three participants said that such a service should provide a list of jobs that were available and might be suitable for them. Furthermore they wanted these jobs to be ones in which their mental health problems were known. An employed man with schizophrenia said '*I think they should have a lot more links with employers. It would be nice to have a list of employers who have been to a week's training on mental health issues and understand the ins and outs . . . and that you don't have to start with a blank slate*'.

DISCUSSION

Working

As in previous studies (MIND, 1993; Secker *et al.*, 2001), when asked for a yes or no response nearly everyone said they wanted to work. However this was frequently followed by the expression of substantial doubts and these initial firm assurances may to some extent reflect the social desirability of work. These initial statements about wanting to work could be described as public accounts (Pope & Mays, 1995), behind which a set of rather more complex and contradictory private accounts emerged on more detailed exploration. That doubts about working and perceived barriers are important seems confirmed by the observation that there was very little evidence of current active job-seeking among the participants. This gap between expressing an interest in employment and actively seeking it is important as there is evidence from the general population (Tano, 1991) as well as in those with SMI (Mueser *et al.*, 2001) that those who are searching for employment are much more likely to be working in the future.

Based on exploration of the views and experiences of the long-term unemployed in the general population, Jahoda (1981, 1982) has identified a range of latent functions of work. Loss of these as well as work's manifest function as a source of financial reward are important in understanding unemployment's psychological and social effects on individuals. Latent functions of work include the imposition of a time structure, participation in a collective purpose and the enlargement of the scope of activities into areas less emotionally charged than family life. These themes, especially the first two, also emerged from our data. For example, working was seen to have many potential advantages including social contact, providing day-

time structure and self-esteem as well as financial gain (although this was later questioned). However, paid work was not seen as the only source of these for the study participants and a functional response to long term unemployment for some people with SMI may be to establish other social roles which yield some of the latent functions of paid work, such as being a carer, an advocate or in voluntary work. Therefore, some people with SMI may feel that looking for paid employment may not currently be the best option given their level of morbidity, discrimination and the other barriers they face and the possibility of having to do very menial work.

Previous unsuccessful experiences of seeking and trying to retain jobs may also strongly discourage active job seeking. Participants' accounts of previous experience of working suggested that they had generally left of their own accord into unemployment or entered acute psychiatric care. This is somewhat different from some US evidence (Becker *et al.*, 1998) in which more than 50% of job terminations were due to the person being sacked, although this sample was made up of assertive community treatment clients. In our group, discrimination seemed to be felt most potently when people tried to return to work. If this pattern is prevalent, the issues in relation to UK laws on disability discrimination are quite complex in that people are not actually being dismissed, which might well be illegal. A rather more complex social process on their return to work results in them feeling that they are not welcome. This corroborates the finding that people with schizophrenia experience a denial of their skills and criticism on their return to work after an illness episode reported in a recent German study on stigma (Schulze & Angermeyer, 2003).

Barriers to working

Patients face external and internal barriers which interact.

External (societal)

Most participants talked about enacted stigma (a mark of disgrace or discredit that marks a person out from others) as an important determinant of their chances in the job market at some point during the interviews and there is substantial evidence for this from previous studies (Manning & White, 1995; Crisp *et al.*, 2000). In particular participants believed that employers were worried about a number of risks including violence, extensive sick leave and the potential for them to be a disruptive influence in the work environment including to their colleagues.

Because of this discrimination people face a difficult dilemma in that they believe they must conceal their illness to get a job, but that doing so seriously jeopardises their chances of keeping it. A solution may lie in persuading employers to accept the risks, educating them about their extent and in making support available to them in trying to deal with problems that may arise. This would be easier to do if services started by identifying a set of reasonably sympathetic employers and steering people towards them as in the IPS model of job placement. Employers might use the provisions in the Disability Discrimination Act 1995 in the UK to make 'reasonable adjustments' in the environment to help keep people working if problems did arise.

In line with previous work (Rinaldi & Hill, 2000) loss of benefits was seen as a major reason not to return to work. The extent of the monetary disincentive to work is large. For example,

a 25 year old man with paranoid schizophrenia who worked for three years before he became ill, has now been unemployed for two years and lives in a one bedroom council flat in Islington is likely to be entitled to a little under £15000 in Department of Health and Social Services (DHSS) benefits. Around £9000 of this is as disposable income (personal communication from Islington Peoples Rights). Assuming a patient works a 40-hour week on the minimum wage of £4.85 they would receive about £10000 a year. Therefore the reservation wage (Berndt, 1991) (the wage at which working becomes economically viable) for those with SMI is high. It would seem that the unemployment and 'benefit trap' for people with mental illness is more significant than for the general population. This is primarily because the more disabled a person is, the more benefits they are entitled to and therefore the higher the disincentive to work (Turton, 2001). The trap is most potent for people who wish to do paid part-time work, as the majority of people in our sample did and this may be the biggest deterrent when considering the move from unemployment. The fear of having difficulty in getting benefits reinstated if an attempt to start work is unsuccessful may be a further limiting factor.

Understandably people reported they would only work if their wage was more than their benefits entitlement. The reported lack of easily accessible information about losing benefits and employment may be partly responsible for the level of concern expressed about this.

Internal (individual)

The internal barriers consist of people's attitudes and beliefs. It is likely that they are reflections of low self-esteem, a loss of motivation and acceptance of unemployment, worries and past experience. These have been reported by participants in other studies regarding work (Basset *et al.*, 2001). They are also similar to the attitudes expressed by the long term unemployed in the general population (Blumenberg, 2002) although those with SMI have the additional burden of their illness.

A minority of participants said they were not well enough to work, although a greater number felt they were well enough to work on a part-time basis only. In addition many people said that working might lead them to become unwell. These fears primarily expressed by those who were unemployed corroborate previous work (Van Dongen, 1996) suggesting that those who are unemployed are more fearful of working than those who are actually employed. The concerns that people expressed with regards to the side effects and practicalities of taking medication may be an impediment to work, which could be addressed by clinicians.

Although participants complained about discrimination from employers some believed that the employers were justified in their concerns. Many people's comments suggested that they accepted these attitudes with a degree of fatalism and felt that there were not good enough reasons for employers to change them. A number of people also talked in a way that was very self-stigmatising with regards to work, and the belief that one is not as able or employable as someone without mental health problems from the outset is likely to act as a severe disadvantage when selling oneself in the labour market. Even though UK legislation requires employers not to discriminate against the disabled and to make reasonable adjustments to allow them to sustain work, many of our sample did not appear to feel they had a right to support in getting access to the roles and experiences that others in society have and to the help they require to be able to realise their potential.

Current service provision

Advice regarding work may reflect mental health professionals' views about the importance and feasibility of employment for those with SMI. Received work advice seemed to have been more stigmatising for the older age (40 plus) group than for younger people. Although the interview guide did not include a direct question about advice regarding employment from mental health professionals, some participants complained about the lack of it and indeed vocational services do not tend to be included in care plans for people with schizophrenia (Lehman & Steinwachs, 1998). As well as hindering people's progress back to employment, this may reinforce low self-esteem and hopelessness with regards to work.

Attending a specialist employment service for those with mental illness was seen as the most helpful source of assistance in getting back to work. The main criticism was that it often directed people into unpaid rather than open employment. Although voluntary work was seen as therapeutic the majority reported that it did not prepare them for competitive employment. This does seem to reflect the conclusions from research into the IPS service model (Drake *et al.*, 1999). However this does not mean that voluntary work has no useful functions in that it can clearly provide many of the latent functions of work.

Given the level of service provision available, it was unsurprising that participants reported that not enough help was offered in relation to employment. As well as wanting practical help in the process of finding work they also wanted services to have links with sympathetic employers and in some ways to be advocates for them with those employers, perhaps helping to resolve their dilemma regarding the conflicting advantages and disadvantages of telling employers about their illness. It appeared therefore that they wanted something very much like the supported employment programmes for which there is good evidence of effectiveness in the US (Crowther *et al.*, 2001).

Limitations of the study

Seven people refused to participate in the study. Although a reason for refusal was not required, several mentioned that they did not want to be recorded on audiotape, despite assurances regarding the security and confidentiality of these. It may be that those who agreed to be interviewed had particularly strong opinions about employment. However, from interviewer observation there was a wide range of illness severity and strength of opinion in the participants. No one interviewed talked about working in the unofficial labour market. It may be that some of those who refused fall into this group and did not want to divulge this about themselves.

The respondents were aware that the interviewer was a psychiatrist. This may have led to socially desirable answers, although the doubts that people expressed about working would temper this view.

Although the participants were selected to represent a full range of characteristics and experiences among people with SMI and therefore to some extent the results will be generalised, the sample size is small and all drawn from a single inner city area. Opinions and attitudes may well be different in areas which are less socially deprived or provide different employment services. There is a need for further research to fill the gap which has thus far existed in the evidence on this issue.

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APPENDIX

Interview guide

What work would mean for the person

Do you want to work?

What kind of work would you like to do?

Do you think there are advantages/disadvantages to working?

How does illness affect ability to work?

What potential problems would there be with you working?

How might your mental health problems affect your ability to work?

Would you find it difficult to work?

What are the perceived barriers to finding work?

What stops you working?

Have you tried to look for work- any problems?

Would you have particular worries about getting paid work?

What worries do you think employers would have in hiring you?

Would you tell them you had a mental health problem?

Current service provision

Have you had contact with services that to get you back to work?

Have you had experience of sheltered or voluntary work-what was it like?

Did it prepare you for competitive employment?

How did it affect your views on getting paid work (if appropriate)?

Have you had experience of competitive work?

What was it like working?

What happened when you stopped working?

Where would you go to get help with finding a job?

Are there particular kinds of help you need in getting work because of your health problems?

Is the help available at the moment that you believe is needed?

What help is not provided that could be?

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Dr Steven Marwaha MSc, MRCPsych, Lecturer in Social and Community Psychiatry, Department of Psychiatry and Behavioural Sciences, Royal Free and University College London Medical Schools, London, UK.

Dr Sonia Johnson MRCPsych, Senior Lecturer in Social and Community Psychiatry, Department of Psychiatry and Behavioural Sciences, Royal Free and University College Medical Schools, London, UK.

Correspondence to Dr Steven Marwaha, Lecturer in Social and Community Psychiatry, Department of Psychiatry and Behavioural Sciences, Royal Free and University College London Medical Schools, Holborn Union Building, Archway campus, Highgate Hill, London, N19 5LW, UK.

Email: s.marwaha@ucl.ac.uk