

Original Articles

Employment status, aspirations and perceptions of support amongst psychiatric service users in Pavia, Italy

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SUMMARY. **Aims** – To describe the employment status of people using mental health service in Pavia, Italy; to explore their employment aspirations and perceptions of support to achieve these; and to test the feasibility of working with service users as researchers. **Method** – Face to face interviews carried out by two service user researchers with a consecutive sample of 200 service users attending the local psychiatric outpatient department using a translated version of a questionnaire developed for previous UK surveys. **Results** – A higher proportion of survey participants (42.5%) were in paid work compared to the UK, but 62.4% of those in work were dissatisfied with their employment. Amongst unemployed participants, 65.2% were interested in gaining employment but only 29.3% were receiving support to do so. Support was mainly limited to referral on to a generic disability organisation. The service user researchers carried out the survey to a high standard and reported benefits from undertaking the work. **Conclusions** – The results indicate a need in Pavia for specialist employment support using the Individual Placement and Support approach. Further development of service user involvement in research is indicated.

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INTRODUCTION

Research has long demonstrated strong links between unemployment and mental ill health (Warr, 1987) and between meaningful occupation, clinical improvement and decreased levels of service use (Wing & Brown, 1970; McKeown *et al.*, 1992). Equally, service users' own accounts vividly illustrate that returning to work, often after years of absence from the labour market, is

one of the most significant milestones in the process of recovering from mental ill health in the social, as opposed to clinical, sense (Deegan, 1988; Ridgway, 2001; Secker *et al.*, 2002). Contrary to fears that work may be harmful for mental health, research also indicates that support to obtain work can improve functioning (McGurk & Mueser, 2004).

The evidence-based approach to employment support, known as Individual Placement and Support (IPS), is now well-documented (Becker & Drake, 2003) and has been shown to have superior outcomes to more traditional approaches involving often lengthy periods of work preparation in the United States (Bond, 2004) and more recently in six European countries (Burns *et al.*, 2007). In the latter study the Italian site, at Rimini on the Adriatic coast, had one of the most successful services. Against a background of accelerating deinstitutionalisation culmi-

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nating in the reform law of 1978, other Italian localities have also introduced employment initiatives, amongst the best known being the work cooperatives established in Trieste (Ramon, 1995). However, the way in which mental health services in Italy are financed and organised means that services can vary considerably between health districts (Piccinelli *et al.*, 2002) and the exemplary services in Rimini and Trieste are by no means available in all health districts.

The province of Pavia is in Lombardy in the prosperous north of Italy. It has a population of some 180,000 and covers a geographical area that includes the city of Pavia and a rural hinterland where rice growing is one of the main industries. The city of Pavia has good transport links to the major northern Italian cities and is within commuting distance of Milan. The most recent labour market information available indicates that the province has a significantly lower rate of unemployment than the national average (4.3% compared with 7.7% nationally; European Employment Service, 2007a).

Adult mental health services in Pavia differ considerably from those in the UK and elsewhere in Italy. There is no equivalent to the UK's community mental health teams; instead the great majority of people experiencing mental health problems are seen at the outpatient department. The district general hospital has one psychiatric ward with 17 beds and a community mental health centre provides a further 12 rehabilitation beds together with day centre facilities. Social workers at the outpatient department do refer people who are eligible for assistance to a generic disability employment organisation, but the eligibility threshold is high and very little specialist employment support provision is currently available for most service users. Although a voluntary sector initiative approximating to a social enterprise and a second church-run project provide a range of work experience for people with mental health problems, both use traditional 'train and place' methods, based on an assumption refuted by numerous studies (Bond, 2004) that people with mental health problems require lengthy training before seeking work. In addition, the two projects reach only a fraction of the service user population. As a result, little is known about the employment status of this population, or about the extent of need for more widespread employment support. This study was therefore designed to ascertain the employment status of people using mental health services in Pavia and to explore their employment aspirations and what support if any they were receiving to achieve these.

An additional important aim was to test the feasibility of working with service users as researchers since this

had not previously been attempted in Pavia. Research evidence indicates that interviews with mental health service users are both more acceptable and more effective when carried out by fellow service users (Clark *et al.*, 1999). The benefits of and issues raised by involving service users in research are increasingly being documented (Trivedi & Wykes, 2002; Mental Health Foundation, 2003) and several studies carried out by service user research groups have been published (Faulkner & Layzell, 2000; Nicholls, 2001; Ramon, 2003; Maddock *et al.*, 2004; SE-SURG *et al.*, 2006). In the context of a survey of service users' employment aspirations, employing service users to carry out the work was clearly particularly apposite and we believed this would not only improve the quality of the study, but would also be of benefit to the service user researchers themselves. For example, carrying out research interviews could help relational and working abilities, reinforce self-esteem and help in changing the stereotype of service users as people with needs, deficits and few capabilities.

The study was undertaken as part of a long term partnership agreement between the European Employment Service (EURES), the Medical Association of Pavia, the University of Pavia and the National Health Service (NHS) in Essex, represented by the Essex Workforce Development Confederation.

METHOD

Survey questionnaire

A questionnaire previously used in the UK (Secker *et al.*, 2002; SE-SURG *et al.*, 2006) was translated into Italian in an iterative process of back-translation by the research team and a professional translator to ensure that concepts that did not transfer well to the Italian context were accurately expressed. Both the English and Italian versions are available from the corresponding author. In addition to data on respondents' sex, age and ethnicity, the questionnaire covered:

- Current daytime activities
- Level of interest in work
- Support currently provided / required to pursue identified goals.

The questionnaire was designed to be used in face to face interviews. Questions were answered from a fixed list of responses with space for any further comments participants wished to make.

Recruitment of service user researchers

Psychiatrists working within Pavia's mental health services were asked to assist with recruiting potential researchers from amongst service users who met the following criteria:

- Currently using outpatient services
- Having an Axis I or II diagnosis
- Not currently experiencing acute mental health problems
- No psychiatric admissions in the previous 4 months
- No learning disability
- A good command of spoken and written Italian.

The psychiatrists were less than enthusiastic and expressed several concerns, the most common being:

- That it could be dangerous for someone with a psychotic diagnosis, even if well controlled, to have contact with people experiencing different mental health problems, especially because the research topic of employment was seen to be sensitive
- That working within a psychiatric facility would reinforce stigma and be a frightening experience for the service user researcher
- That the service user researchers might feel themselves responsible for other service users' care, at the expense of their own mental health.

Nevertheless, two female service users were told about the work and both expressed interest. We therefore met with them to explain the research and what the work would involve, and to assure them that we would provide as much support as necessary. Because the study was unfunded, we also had to make it clear that we were unable to offer payment and the work would therefore be voluntary.

Both women were keen to be involved on these terms and took part in a training programme. This included:

- Reading through the questionnaire together with them, clarifying details, answering questions and asking them for suggestions to improve the interviewing protocol
- Role playing the interview several times, initially with two university researchers (IC and ER), then with each other, with the university researchers observing, and finally without observation.

Throughout the training we reassured the researchers of their abilities, emphasising that it was for these that they had been selected. We made it clear that they could

express doubts and communicate fears and anxieties, and that they were free to change their mind at any time about taking on the work. It was clear that by the end of the training, the researchers had developed sufficient confidence to begin work.

Sampling, recruitment and data collection

Because the great majority of service users in Pavia receive outpatient services, the outpatient department was chosen as the site for sampling and recruitment. Routine data indicated that just under two thousand people (1,992) had been seen at least once at the department during 2006. Based on practical considerations of time and resources, the intention was to recruit a consecutive 10% sample of 200 people visiting the department, with recruitment continuing until the sample size had been reached.

Recruitment took place between 20th March 2007 and 11th May 2007, when 200 questionnaires had been completed. The researchers attended all outpatient sessions and invited all service users in the waiting room to take part in the study, with the exception of those identified by their psychiatrist as experiencing a critical, acute phase. Participants were recruited in two stages. While in the waiting room, they were asked if they would be willing to answer some questions for a study about the employment status of services users. Those who were willing were invited into a private office, where the researcher explained the aims and methods of the study in more detail and obtained written consent for the interview.

Seventy-eight people declined to participate and three were assessed by their psychiatrist as too unwell to be asked. The 200 people recruited therefore represent a sample of 71% of all service users attending outpatients during the data collection period.

The interviews were all carried out by the service user researchers and varied in length from 20 minutes to one hour. During the earlier data collection sessions one of the university researchers was available to assist in case of any difficulty or doubt but when the service user researchers had gained sufficient confidence they worked completely alone.

Data analysis

Data were entered into a Statistical Package for Social Scientists (SPSS) database and analysed to generate descriptive statistics for the whole sample and for subsamples by sex and age.

RESULTS

Survey participants

Of the 200 participants, 112 (56%) were female and 88 (44%) male. They ranged in age from 19 to 70 years old (Table I) but the majority (131; 65.5%) were in their middle years (36- 65 years). Almost all (96.5%) described themselves as of White European origin (193 from Italy, 1 from another European country). Of the other six participants, one was from Asia, three from Africa and two from Latin America.

Table I – Distribution by age.

	Male (n=88)	Female (n=112)	Total (n=200)
19-24	7 (8.0%)	4 (3.6%)	11 (4.6%)
25-35	22 (25.0%)	21 (18.8%)	43 (17.9%)
36-45	28 (31.8%)	28 (25.0%)	56 (23.3%)
46-55	21 (23.9%)	27 (24.1%)	48 (20.0%)
56-65	8 (9.1%)	19 (17.0%)	27 (26.0%)
>65	2 (2.3%)	13 (11.6%)	15 (6.3%)

Although it might be thought inappropriate to include people aged over 60 in a study of employment aspirations, as populations across Europe are aging, the age of

retirement is also rising (e.g. Pensions Commission, 2005). We therefore wished to include the responses of this group, while noting their impact on our results where necessary.

Current daytime activities

Participants were asked to select their current daytime activities from a given list (Table II). Around a fifth (21%) reported no regular activity. Less than half (85; 42.5%) reported having a paid job. Fifty-five were full time employees, 20 were part time employees, seven were self-employed and three were in paid supported work. There was little difference in the proportions of men (34; 61.4%) and women (51; 54.5%) in paid work.

Fourteen of the 15 participants aged over 65 and the majority of those aged between 56 and 65 (22; 81.5%) were not in paid work. The responses of these older age groups to subsequent questions about interest in obtaining work suggest that many considered themselves to be retired (see next section).

The other activities described by 23 participants (11.5%) included attending to pets or to farm animals, taking care of older relatives and hobbies.

Table II – Current daytime activities (multiple answers possible).

	Male (n=88)	Female (n=112)	Total (n=200)
Day centre	16 (18.2%)	8 (7.1%)	24 (12.0%)
Formal training/education	7 (8.0%)	6 (5.4%)	13 (6.5%)
Paid supported work	2 (2.3%)	1 (0.9%)	3 (1.5%)
Full time work	23 (27.3%)	32 (28.6%)	56 (28.0%)
Part-time work	4 (5.7%)	16 (14.3%)	21 (10.5%)
Self employed	5 (5.7%)	2 (1.8%)	7 (3.5%)
No paid work	64 (61.4%)	61 (54.5%)	115 (57.5%)
Collaboration in family activity	7 (8.0%)	6 (5.4%)	13 (6.5%)
Voluntary work	5 (5.7%)	8 (7.1%)	13 (6.5%)
Housework	1 (1.1%)	9 (8.0%)	10 (5.0%)
Other activity	10 (11.4%)	13 (11.6%)	23 (11.5%)
No regular activity	25 (28.4%)	17 (15.2%)	42 (21%)

Interest in work

The 85 participants who were in paid work were asked if they were interested in improving their employment situation, for example by getting a better job or extending their hours of work. Twenty-five (29.4%) were satisfied with their situation but 53 (62.4%) were definitely interested and a further six were possibly interested (one person did not know). There was little difference in the proportions of men and women expressing an interest. Of the

34 men in this group, 23 (67.6%) were interested, compared with 36 (70.6%) of the 51 women.

Participants who were not in paid work were asked if they were interested in getting a job, if obstacles such as incompatibility with disability pensions could be overcome. A third (40; 34.8%) was not interested. Sixty-two people (53.9%) were definitely interested and 13 (11.3%) said they might be interested in the future. Interest was higher amongst the 54 men in this group (81.5% interested) than amongst the 61 women (50.8% interested).

Participants in the older age groups accounted for a substantial proportion (55%) of those who were not interested in work, suggesting that many of this group did see themselves as retired. Twelve of the 14 unemployed people aged over 65 (85.7%) and ten of the 22 aged 56-65 (45.4%) had no interest in work.

Of the 75 unemployed people who were interested, most (35; 46.7%) were interested in part time work. Twenty-six (34.7%) were interested in full time work and seven (9.3%) were interested in either full or part time. Only three people (4%) were interested in self-employment, in one case as an alternative to full time employment. Two people (2.7%) were interested in any kind of work and two did not know.

The preference for part time work was largely accounted for by female participants. Nineteen of the 31 women in the unemployed group (61.3%) expressed this preference, compared with 16 (36.4%) of the 44 men.

Vocational support currently received and required

Unemployed participants who expressed an interest in work were asked if they were currently receiving support to achieve this goal. Only 22 of the 75 (29.3%) reported receiving support, mainly consisting of being referred on to a generic disability employment organisation. The highest proportion of unmet need for support was amongst women, of whom only seven (22.6%) were receiving support, compared with 15 (34.1%) of men.

Participants were then asked to indicate if they would like support, or more support than they were receiving, and if so to select the support required from a given list (Table III). Once they had made their selection, they were asked to indicate the type of support they thought most important (Table IV).

Table III – Support wanted to find work (multiple responses possible).

	Male (n=44)	Female (n=31)	Total (n=75)
Help to find a paid job in the open job market	25 (56.8%)	15 (48.4%)	40 (53.3%)
Help to deal with health problems	13 (29.5%)	13 (41.9%)	26 (34.7%)
Work placement or work experience in an ordinary job situation	12 (27.3%)	8 (25.8%)	20 (26.7%)
Support once I'm in work for as long as I need it	7 (15.9%)	10 (32.3%)	17 (22.7%)
Job in sheltered supported situation	9 (20.5%)	7 (22.6%)	16 (21.3%)
Advice on how my benefits will be affected if I go to work	7 (15.9%)	7 (22.6%)	14 (18.7%)
Training on job finding skills	6 (13.6%)	5 (16.1%)	11 (14.7%)
Voluntary work (full-time or part-time)	3 (6.8%)	7 (22.6%)	10 (13.3%)
Help with childcare and/or caring for other dependants	7 (15.9%)	3 (9.7%)	10 (13.3%)
Careers advice	3 (6.8%)	6 (19.4%)	9 (12.0%)
Help and advice on becoming self-employed	1 (2.3%)	2 (6.5%)	3 (4.0%)
Other kinds of help	1 (2.3%)	1 (3.2%)	2 (2.7%)
None	8 (18.2%)	8 (25.8%)	16 (21.3%)

Table IV – Most important support.

	Male (n=44)	Female (n=31)	Total (n=75)
Help to find a paid job in the open job market	13 (29.5%)	4 (12.9%)	17 (22.7%)
Help to deal with health problems	4 (9.1%)	10 (32.3%)	14 (18.7%)
Work placement or work experience in an ordinary job situation	5 (11.4%)	3 (9.7%)	8 (10.7%)
Job in sheltered supported situation	3 (6.8%)	1 (3.2%)	4 (5.3%)
Advice on how my benefits will be affected if I go to work	2 (4.5%)	1 (3.2%)	3 (4.0%)
Help with childcare / caring for other dependants	2 (4.5%)	1 (3.2%)	3 (4.0%)
Voluntary work full-time or part-time	2 (4.5%)	0	2 (2.7%)
Careers advice	1 (2.3%)	1 (3.2%)	2 (2.7%)
Support once I'm in work for as long as I need it	0	1 (3.2%)	1 (1.3%)
Training on job finding skills	1 (2.3%)	0	1 (1.3%)
Doesn't know	3 (6.8%)	1 (3.2%)	4 (5.3%)
Help and advice on becoming self-employed	0	0	0
Other kinds of help	0	0	0

Only 16 people (21.3%) said they did not need support. As Tables III and IV show, amongst the other 59 participants the most frequently identified types of support required and the most important were very similar,

with help to find paid work the most frequently identified type of support and the most important, followed in both cases by help to deal with health problems and work experience in an ordinary job situation. However, there

was a clear gender reversal in the first and second rankings. Help to find paid work was selected as most important by 29.5% of the men but only 12.9% of the women. Conversely help to deal with health problems was selected as most important by 32.3% of the women but by only 9.1% of the men.

Although almost a quarter (21.3%) of the 75 participants identified obtaining a job in a sheltered setting as potentially helpful, only 4 (5.3%) ranked this as most important. The difference in frequency ratings and rankings for time unlimited support once in work (identified as potentially useful by 22.7% but ranked most important by only one participant) probably reflects the distance from the labour market of this unemployed group.

DISCUSSION

The results reported above reveal a striking difference in employment status amongst service users in Pavia and those areas of England where similar surveys have been carried out. Whereas 42.5% of service users in Pavia were active in some way in the labour market, in England the highest rate found is 15% (SE-SURG *et al.*, 2006). Since unemployment rates in England are only slightly higher than in Pavia, at 5.5%, it is unlikely that general labour market conditions account for the difference. Rather, the explanation may relate in part to differences in the mental health status of the study samples. It is not possible to systematically compare the samples because in both England and Pavia it was considered inappropriate to ask for diagnostic information, since diagnostic categories can be seen by service users as objectionable or too sensitive to report to non-clinical researchers. However, in the English surveys, the samples were drawn from people on the enhanced Care Programme Approach and would therefore have predominantly comprised people experiencing severe and enduring problems rather than the more common problems such as anxiety and depression. In the UK these more common problems are treated for the most part not within specialist mental health services but in general practice (Sainsbury Centre for Mental Health, 2007). In contrast, in Pavia everyone with a psychiatric diagnosis is treated within specialist services and the Pavia sample might therefore be expected to include a higher proportion of people with less disabling problems than in England.

A further factor seems likely to be differences in the UK and Italian welfare benefit systems (Tibaldi *et al.*, 2006). To receive a disability pension in Italy an individual must be medically certified as having a disability that

makes it permanently impossible to carry out any type of work (European Employment Service, 2007b). It is therefore likely that the fluctuating nature of mental health problems makes it more difficult for people to claim benefits than in the UK, where eligibility for incapacity benefit is determined at the time of a personal assessment and the criterion of permanency does not apply (Department for Social Development, 2005).

Turning to the other results from Pavia, two thirds of participants who were not already in paid work aspired to a job, but few reported receiving help to achieve this goal. Equally, two thirds of those who were in paid work wished to improve their employment conditions. Despite the relatively high proportion of people in work these results point to a need to develop specialised employment support provision within Pavia's mental health services. The survey results also indicate that employment support should be provided in line with the IPS approach, as opposed to the more traditional train and place model. Help to find paid work in the open job market is a key emphasis of IPS, and this was both the most frequently identified and the most important type of support identified by the Pavia participants. Providing time unlimited support in work is also a key feature of IPS and this too was amongst the most frequently identified types of support required. Within the IPS approach, support in work involves not only assisting in the resolution of problems, but also enabling people to develop their career. In addition to meeting the needs of unemployed service users, the IPS approach could therefore be of benefit to people in work who wish to improve their employment situation. In developing employment support provision, it will be important to take account of the particular needs of women, who accounted for the highest proportion of unmet need for support.

Service users as researchers

Working with service users as researchers was one of the most exciting aspects of the research for the team in Pavia and was possible because of the enthusiasm, personal involvement, passion and reliability of the two researchers themselves. The work was not without challenges for them, as they had to overcome some embarrassment about their role and about asking participants questions about their lives and work. One researcher completed her first day's work but did not return the next day, explaining that she was not at ease in the role. However, with support from the university researchers (IC and ER) she gradually came back to work and both

researchers completed their duties with no further problems. Although data collection was initially slow as both women needed reassurance from the university researchers, particularly about how to introduce themselves to potential participants, once they gained confidence they worked autonomously and the time needed for the interviews decreased. They demonstrated a clear understanding of the aims of the study, conducted the interviews well and completed the questionnaires with no major mistakes.

Once data collection was completed, a debriefing was arranged to verify the work done and ask the researchers about their impressions and feelings about it. In order that they could be as honest as possible, they were asked to write about their experiences in response to open questions. Both researchers expressed satisfaction with the work and gratitude for the opportunity to undertake it. They wrote of discovering in themselves qualities they had never used and of feeling useful. They both spontaneously affirmed their interest in repeating such an experience, although one researcher did add that it would have been better to be paid. We are in full agreement with this point and are aware that asking service users to carry out skilled work over a continuous period of several weeks could be seen as exploitative. As the response of the psychiatrists who were asked to help with their recruitment makes clear, however, the idea that service users might be able to carry out research work does not appear to be fully accepted in Italy and one of our aims was to test out this approach. Both women understood that the work was voluntary and were keen to undertake it on this basis, and both felt they had benefited from the experience. Under these circumstances, we would argue that our approach was justified, but that in future studies involving service users in such extensive roles it will be important to ensure that payment is available.

More detailed development of criteria for the selection of service user researchers may also be useful, but we would caution against excluding individuals from employment of this type on the basis of clinical factors, since extensive studies have shown that when people are motivated to do a job and have appropriate support, clinical factors are not a strong indicator of success (Grove & Membrey, 2005).

CONCLUSIONS

Results from our survey of employment status and aspirations in Pavia indicate a need for the establishment of an evidence based IPS employment service within the

province's mental health services. Although a higher proportion of participants were in work, compared to the UK, many of those in work were dissatisfied with their employment conditions and amongst those who were unemployed aspirations to work were widespread. The experience of working with service user researchers was very positive. In one area of England, the opportunity for service users to work on the survey there led to the foundation of the South Essex Service User Research Group (SE-SURG). The group is now well established and carries out research for commissioners and providers of mental health services, with payment commensurate with members' individual financial situation. The establishment of a similar group in Pavia is a further ambition for the future. As a starting point, we are planning a presentation of the findings of this survey to service users of the outpatient department in Pavia.

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