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Still dreaming: service users' employment, education & training goals

The South Essex Service User Research Group (SE-SURG)

with

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# Still dreaming: service users' employment, education & training goals

#### Abstract

# **Background**

Enabling service users to find and keep real jobs is a significant strand of UK mental health policy. An evidence based approach to employment support is well documented, but is not widely implemented in the UK.

### Aim

To inform the development of vocational services in South Essex by ascertaining service users' employment, education and training goals.

### Method

Face to face interviews with a randomly selected sample of service users on enhanced CPA carried out by a team of service user researchers using an adapted version of a questionnaire developed for a previous similar survey. Postal survey of a further randomly selected sample of service users on enhanced CPA using a brief version of the questionnaire.

### Results

Interviews were carried out with 82 service users. A further 159 returned a postal questionnaire. 42.7% had no regular day time activity. Only 15% were in paid work. 60.6% were definitely interested in finding work. 77% of respondents to the interviews who were interested in work were not currently receiving support to achieve this. The main help wanted was support in work, help with mental health problems and benefits advice. The main barriers identified were employers' attitudes and threat to benefits. Service user researchers reported benefits from undertaking the work.

# **Conclusions**

High numbers of mental health service users are interested in pursuing employment, education or training goals but currently lack the support they need to do so. Implementation of an evidence based approach to employment support has the potential to enable service users to achieve their goals. Service users are well able to undertake research with considerable benefits for themselves and other stakeholders.

# Declaration of interest

None.

**Keywords:** Mental health; employment; service user research

### 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 and 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). Enabling mental health service users to find and keep real jobs is also seen as key both to mental health promotion (Department of Health, 1999), and to social inclusion (Office of the Deputy Prime Minister, 2004).

An evidence-based approach to employment support, known as Individual Placement and Support (IPS), is now well-documented (Becker and Drake, 2003) and has been shown to have superior outcomes to more traditional approaches involving often lengthy periods of work preparation (Crowther et al., 2001). At present, however, IPS has not been widely implemented in the UK and there is still considerable doubt amongst mental health professionals that service users want to and are able to work (Office of the Deputy Prime Minister, 2004).

Historically, the South Essex locality reflected this national picture. A benchmarking exercise carried out in 2002 indicated that vocational services were provided primarily by voluntary sector projects with limited involvement from statutory services and that some staff across both sectors doubted whether local service users were sufficiently interested in work to warrant the development of more extensive services. The present survey was therefore commissioned in order to assess the extent of service users' vocational aspirations. Ethics and research governance approvals were granted for the study in January 2004 and the survey was carried out by a team of service user researchers between February and December 2004.

### Method

# Recruitment of service user researchers

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 and Wykes, 2002, Mental Health Foundation, 2003), a national service user research group has been established to work with the National Institute for Mental Health in England's research network and several studies carried out by service user research groups have been published (Faulkener and Layzell, 2000; Nicholls, 2001; Ramon, 2003; Maddock et al., 2004). In the context of a survey of service users' vocational goals, employing service users to carry out the work was clearly particularly apposite.

An invitation to join the research team was initially extended in December 2003 to service users who were completing a Pathways to Empowerment course provided in South Essex by Anglia Polytechnic University (APU). Other members of the team were

recruited from two voluntary sector employment projects. All those who expressed interest were invited to attend an information meeting where the work involved and the payment available was explained. Of a total of 13 people who attended this meeting, ten joined the research team. A further member was recruited after hearing about the study via a Mind project and these 11 researchers completed the study.

At a second meeting, information was provided about welfare benefit rules so that people could make an informed choice about payment options. One member of the team who was ready to come off benefits was employed at APU for two days per week as survey administrator.

Further meetings were held at six-weekly intervals throughout the study period. During the early meetings research team members role-played the survey interview and made valuable suggestions regarding its layout and wording. Subsequent meetings were held to feedback on progress, provide support as necessary and deal with administrative matters.

# Sampling and recruitment

Routine data collected at SEPT indicate that some 2,500 people are on enhanced CPA at any one point in time in the South Essex area. The initial intention was to recruit a 10% sample of this population to take part in face to face interviews. With the assistance of the Trust's Information Directorate, letters inviting participation and an information sheet were mailed to 650 service users selected at random using Excel software. A reply slip and prepaid envelope were enclosed for those interested in taking part to provide contact information.

Just over 100 people responded to this initial invitation. In order to move closer to the intended sample size of 250, a postal version of the survey questionnaire was mailed to a further randomly selected sample of 650 service users, together with a prepaid envelope for their response.

### Data collection

A questionnaire previously used by Secker et al. (2001) in Sheffield was adapted for use in South Essex with input and advice, as noted above, from the service user researchers. In addition to data on respondents' locality, sex, age and ethnicity, the questionnaire covered:

- Current daytime activities
- Level of interest in work, education and training
- Support currently provided / required to pursue identified goals (face to face interview only)
- Perceived barriers to employment (face to face interview only).

Face to face interviews were arranged by the survey administrator in liaison with research team members. Most interviews took place in community venues such as a local café. Where a respondent was unable to leave home, for example because of a disability, two researchers visited to carry out the interview. The interviews varied in length from 20 minutes to one hour, depending on the time required to put the

individual at ease and ensure they understood the reasons for the study and how their contribution would be used.

A briefer version of the interview questionnaire omitting the more detailed questions about support received/required and perceived barriers was used for the postal survey as indicated above. Copies of both questionnaires are available on request from the corresponding author.

# Data analysis

With assistance from a member of the service user research team, the survey administrator entered data from both the face to face and postal questionnaires into a Statistical Package for Social Scientists (SPSS) database. The data were analysed at APU (by LG) to generate descriptive statistics for the whole sample, and for subsamples by sex and locality. Sample sizes for age and ethnicity were too small for meaningful separate analysis. Since the locality data are primarily of interest to the local PCTs, only the breakdown by sex is reported here where this is particularly pertinent.

### **Results**

# The survey respondents

In total 82 people took part in face to face interviews and a further 159 completed the postal questionnaire. Based on information from the Trust's Information Directorate, the geographical distribution of respondents reflects patterns of service use across South Essex. Just over half (52%) the respondents were female, a proportion also commensurate with patterns of service use across South Essex. They ranged in age from 19 to over 65 years. Unsurprisingly for this area of England, the majority of respondents (n = 200, 83.0%) described themselves as of White British origin. However, 11.1 % were from Black and minority ethnic groups, compared with a local population of 5.6%.

### Current daytime activities

Respondents to both the face to face interview and the postal questionnaire were asked to select all the regular daytime activities in which they currently engaged from the list in Table 1. Over two-fifths of respondents (42.3%) said they had no regular daytime activities. Only 14.9% were in any kind of paid work (supported, full time, part time or self-employed) and only 12.4% were undertaking any formal education or training.

Almost a third of respondents indicated that they did have daytime activities other than those listed and these illustrate a wealth of motivation, talent and experience. For example, respondents mentioned taking regular exercise, such as cycling, swimming or walking, or participating in arts activities such as writing, drama, painting and craftwork.

Table 1 about here

A slightly higher proportion of women (18.4%) than men (11.6%) were in paid work and more women were also involved in voluntary work. Conversely, a smaller proportion of women had no regular activity or were attending day centres and drop ins.

## Interest in work, education or training

All respondents who were not in paid work were asked if they would be interested in obtaining work, either now (yes) or in the future (maybe). Table 2 shows the responses for the sample and for men and women. Of 193 respondents who responded to the question, 60.6% (n = 117) were interested in paid work now, with a further 10.4% (n = 20) interested in gaining paid work in the future. Only 56 respondents (29.0%) had no interest in paid work. The level of definite interest was higher amongst men than women (67.0% compared with 54.2%). Conversely, the proportion of women maybe interested in the future was almost twice that for men and the proportion not interested at all was also higher.

### Table 2 about here

Of the 82 people who participated in the face to face interviews, only nine were not interested in paid work. These nine respondents were asked if they were interested in any education or training instead. One person was definitely interested, four were maybe interested in the future and three were not interested (no response was recorded in one case).

For simplicity, all respondents to the postal questionnaire were asked if they were interested in any education or training, regardless of whether they were also interested in paid work (see Table 3). Of the 154 people who responded to this question 61.7% (n = 95) were definitely interested, with a further 2.6% (n = 4) maybe interested in the future. Men and women expressed similar levels of interest.

### Table 3 about here

# Vocational support currently received and required

Respondents to the face to face interviews who expressed an interest in obtaining paid work (n=61) were asked if they were currently receiving help to achieve their goal. Forty-seven (77%) were receiving no help. Of those who were receiving help, five mentioned voluntary sector projects, two their social worker, two their college and two the jobcentre. One respondent identified art therapy as helping her towards work.

Respondents to the face to face interviews who were receiving help were asked if they would like more help, and if so what kind of help they needed. Those who were not receiving help were asked what kind of help they needed. Both groups could select as many options as they wished from the list in Table 4. As the figures indicate, support once in work, help to deal with mental health problems in relation to work, benefits advice and education or training were the most frequently selected, by around three quarters of respondents.

### Table 4 about here

# Perceived barriers to paid employment

All respondents to the face to face interviews, whether in work or not, were asked to identify barriers to paid employment for mental health service users. They could select as many as they wished from the list shown in Table 5. Everyone identified multiple barriers and each barrier was selected by at least 30%. The most frequently selected were employers' attitudes and threat to benefits. Approximately two thirds of respondents singled out lack of skills and health problems. Also important were lack of work experience, insufficient support, age and the fear that mental health services would be withdrawn if they found work. The 'other' barrier most frequently identified related to stigma, in terms of public and colleagues' attitudes or fear of disclosing mental health problems.

Table 5 about here

# Discussion

Surveys of this kind raise questions about whether the views of those who chose to respond are representative of service users' views more generally across South Essex. In particular, it might be argued that people with an interest in work, education or training would be more likely to opt into the study than those with no interest. However, the sample was broadly representative of service users on enhanced CPA in the locality and although most respondents were interested in work, education or training, just under one third were not, suggesting that those with no interest were not put off from responding.

The results are also similar to those of previous surveys in terms of the level of interest in work and the barriers identified (Bates, 1996; Rinaldi and Hill, 2000; Secker et al., 2001). While this strengthens the reliability of the results, it may suggest that the survey contributes little in the way of new knowledge. However, the previous surveys were all carried out in large cities (Nottingham, London and Sheffield). In contrast, the South Essex locality comprises smaller towns and is a relatively affluent area, albeit with pockets of socio economic deprivation. Arguably, further local studies of this kind are needed in diverse localities, particularly rural localities, before we can be confident that we do understand service users' vocational aspirations across the UK. In the meantime, the present survey suggests that service users in areas such as South Essex share the aspirations and face similar barriers to those in the larger cities.

Turning to the results, there is little doubt that more extensive vocational services are required in South Essex to meet service users' aspirations and needs. Only 14.9% of survey respondents were in any kind of paid employment, compared with 21% nationally (Disability Rights Commission, 2004). Almost two thirds of those not in work would like a job and the level of interest in education and training was also high. Yet over three quarters of these service users were receiving no help to achieve their goals.

The survey results also indicate that the vocational services developed to meet local need should be based on the IPS approach (Becker and Drake, 2003), in terms of both the model of service delivery and the type of help required. Where the model of service

delivery is concerned, the evidence base is clear that integrating vocational services with community mental health teams is more effective than separate delivery of vocational and mental health services. Survey respondents reported that ongoing help to address mental health problems in relation to work, education or training was important to them and were fearful that services might be withdrawn if they articulated their goals to mental health staff. The integration of vocational and mental health services is key to addressing these concerns, ensuring that service users are able to pursue their goals with appropriate support. The types of help survey respondents most frequently identified are also key elements of the IPS approach: support in work for as long as necessary, help with mental health problems in relation to work and benefits advice.

# The service user researcher experience

In addition to both informing the development of vocational services in South Essex, and contributing to knowledge of UK service users' vocational aspirations, the study builds on the growing experience of service users in carrying out research. The service user researchers' comments and discussions at meetings reflected the fact that through both meeting as a group and carrying out individual interviews they gained an insight into the lives of others and broadened their own knowledge and understanding. Towards the end of the study period, the researchers were offered the opportunity to comment anonymously in writing about their experience of being involved in the survey. Their comments reflect an appreciation of the knowledge and skills gained, the opportunity to draw on their experience of mental ill health in enabling others to express their views and in particular a sense of being accepted and given responsibility for important work regardless of their diagnosis. Amongst the benefits mentioned were increased confidence, the financial rewards available and valuable experience to include in their CV.

Participation in the survey work also led to employment outcomes beyond what might have been expected for temporary work of this kind. As noted earlier, one of the original volunteers was able to move off benefits and take up the post of survey administrator, with support from staff at a voluntary sector employment project, providing her with not only a regular income but more importantly a worthwhile activity which has assisted in increasing her self esteem and independence. Other members of the group have since taken up paid work and some have also assisted with other research projects for which they have received a fee.

In terms of the potential limitations of service user research, few problems were experienced. Researchers were able to choose how much work they took on at any time in line with what they felt able to do and their financial situation, and no one had to leave the research group due to mental health or other problems. One limitation, however, concerned the limited hours people on means tested benefits were able to work each week without losing benefits. This meant that the face to face interviews, which might in other circumstances have been completed in a month or six weeks, had to be carried out over an extended period of several months. In addition, the timescale for completion of the study meant there was no opportunity for the researchers to receive training to enable them to carry out the data analysis, hence, as noted earlier, this was carried out at APU. On the other hand, the creativity, enthusiasm and reliability of the researchers more than compensated for these drawbacks.

## Progress in South Essex

Since completion of the survey, significant progress has been made in South Essex towards implementation of an employment strategy to meet the needs identified by survey respondents. An evidence-based strategy has been approved by the Trust Board and an Employment Strategy Implementation Group established. Based on experience at South West London and St. Georges' NHS Mental Health Trust (Davis and Rinaldi, 2004), a Vocational Services Manager has been appointed at Assistant Director level with a remit to develop a Vocational Services Unit. Once fully established, the unit will comprise one vocational specialist located with the community mental health teams in each of the five PCT areas covered by the Trust. Currently two vocational specialists are in post and discussions regarding the remaining three posts are underway with the relevant commissioners An important aspect of the manager's role is to establish a system to monitor service use, record the outcomes achieved and highlight any gaps in the service that require to be addressed, for example under use of the service by women or people from minority ethnic groups. Working with local employers and ensuring that impartial benefits advice is available to everyone contemplating work are key tasks for the vocational unit as a whole.

A further spin-off from the survey is the establishment of SE-SURG, the South Essex Service User Research Group, funded by SEPT from NHS R&D resources. New service user researchers are being recruited to join the original survey group and SE-SURG will provide a user-led research service to providers and commissioners of mental health services in the locality and beyond. In addition, the creation of a more established group will enable members to make greater use of opportunities to receive training in data analysis and other aspects of the research process than was possible within the timescale of the survey.

# Conclusion

In common with previous research, the South Essex survey demonstrates that high numbers of mental health service users are interested in pursuing employment, education or training goals but currently lack the support they need to do so. In addition, our results indicate that implementation of the IPS approach to employment support, particularly the co-location of vocational specialists within CMHTs and the provision of support in work for as long as necessary, has the potential to enable service users to achieve their goals. Not least, the survey demonstrates that service users are well able to undertake work such as this study that might historically have been thought too complex and specialised, and that they and other stakeholders in mental health services have gained significant benefits as a result.

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**Table 1. Regular daytime activities (all respondents)** 

	*Male	*Female	All
	n %	n %	n %
Day centre	16 (14.2)	7 (5.6)	24 (10,0)
Drop-in centre	17 (15.0)	16 (12.8)	34 (14.1)
Formal training/education	14 (12.4)	16 (12.8)	30 (12.4)
Supported work	1 (0.9)	2 (1.6)	3 (1.2)
Work experience	3 (2.7)	1 (0.8)	4 (1.7)
Full-time work	3 (2.7)	8 (6.4)	11 (4.6)
Part-time work	7 (6.2)	9 (7.2)	16 (6.6)
Self-employed	2 (1.8)	4 (3.2)	6 (2.5)
Voluntary work	11 (9.7)	25 (20)	36 (14.9)
Other	31 (27.4)	45 (36.0)	76 (31.5)
No regular activity	55 (48.7)	46 (36.8)	102 (42.3)

<sup>\*3</sup> respondents to the postal survey did not indicate their sex

**Table 2. Level of interest in paid work (all respondents)** 

	Yes	Maybe	No
	n (%)	n (%)	n (%)
All	117 (60.6)	20 (10.4)	56 (29.0)
Men	63 (67.0)	7 (7.4)	24 (25.5)
Women	52 (54.2)	13 (13.5)	31 (32.3)
*Unknown	2 (1.0)	=	1 (0.5)

<sup>\* 3</sup> respondents to the postal questionnaire did not indicate their sex

**Table 3. Level of interest in education or training (postal respondents only)** 

	Yes	Maybe	No
	n (%)	n (%)	n (%)
All	95 (61.7)	4 (2.6)	55 (35.7)
Male	45 (60.0)	2 (2.7)	28 (37.3)
Female	50 (63.3)	2 (2.5)	27 (34.2)

**Table 4. Vocational support required (face to face respondents only)** 

	n (0/)
	n (%)
Support once in work for as long as needed	48 (78.7)
Help to deal with mental health problems	47 (77.0)
Advice on how benefits will be affected	45 (73.8)
Training or education	44 (72.1)
Job in sheltered, supported situation	23 (37.7)
Work placement/experience	27 (44.3)
Voluntary work	29 (47.5)
Higher education	21 (34.4)
Careers advice	27 (44.3)
Training on job finding skills	38 (62.3)
Help to find a paid job in open market	28 (45.9)
Help and advice on becoming self-employed	15 (24.6)
Help with childcare	5 (8.2)

**Table 5. Perceived barriers to employment (face to face respondents only)** 

	n %
Employers' attitudes	62 (75.6)
Threat to benefits	58 (70.7)
Not having the skills or qualifications	54 (65.8)
Health	51 (62.2)
Lack of work experience	49 (59.8)
Not having enough support	45 (54.9)
Age	44 (53.7)
Fear that mental health services withdrawn	43 (52.4)
Lack of vacancies	30 (36.6)
Transport services	29 (35.4)
Mobility	28 (34.1)
Caring for dependents	25 (30.5)
*Other	24 (29.3)

<sup>\*</sup>Some respondents described more than 1 'other' barrier