

Life's Labours Lost

**A study of the experiences of people who
have lost their occupation following
mental health problems**

Richard Bodman, Rosie Davies, Nancy Frankel,
Lea Minton, Lyn Mitchell, Christiane Pacé, Ruth Sayers,
Nigel Tibbs, Zena Tovey and Elise Unger

Acknowledgments

We have had a lot of support while doing this research. Much appreciation to the Strategies for Living team, with particular thanks to Sarah Wright, who has been unfailingly helpful and supportive, a great source of information and has run most of our training. Thanks also to Bristol Mind, particularly Jon Fowler from the User Focussed Monitoring project, and Jeff Walker, the Co-ordinator, for use of computer facilities, access to a photocopier, free meeting space and many cups of tea!

We also thank everyone who has taken part in our research. Without our participants we would have nothing to say. People gave their time and energy very generously in contributing to this study. We particularly thank the five people who took part in interviews: the two who did our pilot interviews and the three whose stories appear as case studies. We have been very encouraged by people who have expressed interest in the project, who have invited us to speak at conferences and workshops and who have already given us the opportunity to share what we have learned.



For copies of the report or more information you have the following options:

Email: Rosie Davies rosie@davies7775.fsnet.co.uk
Ruth Sayers ruthsayers@yahoo.co.uk

Write: c/o User Focussed Monitoring Project
Bristol Mind, PO Box 1174, Bristol BS99 2PQ

Telephone: c/o User Focussed Monitoring Project 0117 373 0336

Full report: Mental Health Foundation's website: www.mentalhealth.org.uk
Bristol Mind's website: www.bristolmind.org.uk

A four page summary of the research can be found on the Mental Health Foundation's website www.mentalhealth.org.uk or obtained from the Publications Department, The Mental Health Foundation, 83 Victoria Street, London SW1H 0HW, telephone Customer Services 0207 802 0300.

Please send an A4 self-addressed envelope with postage (69p second class) c/o the User Focussed Monitoring Project if you would like a copy of the full report.

Life's Labours Lost, October 2003

The research team was led by Ruth Sayers and Rosie Davies. The research was initiated by Ruth Sayers who wrote the research proposal accepted by the Strategies for Living project. The report was written by Rosie Davies with contributions and support from others in the team.

© 2003 Richard Bodman, Rosie Davies, Nancy Frankel, Lea Minton, Lyn Mitchell, Christiane Pacé, Ruth Sayers, Nigel Tibbs, Zena Tovey and Elise Unger

Contents

	Page
Preface	1
Introduction	2
Methodology	4
Findings	
The Impact of Loss	7
The Effects on Identity	13
The Effects of Stigma	16
What Participants Found Helpful and Unhelpful	20
A Journey Without a Map	26
Case Study - Emily	
Case Study - Robert	
Case Study - Chloe	
Discussion	34
Stigma and Discrimination	
Work-Life Balance	
Identity	
Valuing Skills	
Getting Back to Occupation	
The Need for Specialist Services for All	
Flexible Workplaces	
A New Framework	
Final Comments	
Recommendations	42
References	45
Reading List	46
Appendix 1: Questionnaire: including all questions asked and statistical results	

Charts

Chart 1 : Age range of Sample

Chart 2 : Years since leaving occupation

Chart 3 : Comparison of the impact of loss of occupation with other effects of mental health problems

Chart 4 : Negative, neutral and positive effects of loss of occupation

Chart 5 : Change from previous to current levels of responsibility hours and pay

Chart 6 : Stigma issues in taking up work again

Chart 7 : Comparison of current voluntary or paid work or study with previous work

Chart 8 : How people rated the importance of issues about taking up work again

Chart 9 : Factors helpful for returning to an occupation: most highly rated

Chart 10 : Factors helpful for returning to an occupation: less highly rated

Preface

The origins of this research lie in the personal experience of one team member who lost her job as a result of mental illness. This loss was deeply painful and utterly disrupted future expectations. In time, it led her to submit a successful application to Strategies for Living¹ to do research in this area. A research team of ten was formed. Reasons for involvement varied as did our experiences, but we shared a personal interest in the subject. We have all experienced losses that have changed our sense of self, damaged our confidence and led to difficulties in finding meaningful occupation.

Doing research in a user-led team has brought its rewards and challenges. We have met and worked within an accepting group with shared interests. We have felt a sense of achievement and been daunted by the volume of work. Some of our meetings have been very stimulating as we discussed ideas, shaped the questionnaire and worked through the findings. We have had fun together. We have learnt research skills and made links with other projects. We have conducted presentations at conferences, workshops and at local mental health service meetings.

People have made varying contributions; some team members were only involved in parts of the project. A number of us have been ill and needed to take time out, or do less. Some have dropped out because other commitments took priority. We have had to negotiate different expectations and how responsibility was to be shared and this has been difficult. The project needed quite a lot of leadership and organisation, and two people shared this role.

Keeping the project manageable has been hard. It has been difficult to keep our aims in mind - sometimes it was hard to remember what they were! It has been hard to meet deadlines when, as volunteers, we have very different priorities. The project has generated stress and circumstances have led to one person doing most of the writing.

We have got different things from our involvement: made friends, learnt new skills, had opportunities to speak in public. At times participating was demanding, frustrating and stressful. In the life of the project, two team members have had bad experiences in paid work which have triggered or compounded mental health problems; another has taken on full time work which has been positive so far.

We have done this research because we want things to change. Our ongoing challenge is to see how we can make our work count and find people who want to listen.

¹ The Strategies for Living Project supports user-led research and is based at the Mental Health Foundation.

Introduction

Background to our research

This project is based on concerns about people with mental health problems who have limited access to meaningful activity or occupation and are socially excluded. In this project we have defined occupation as engaging in some kind of paid or voluntary work (however few hours) or study.

We feel this research is important because many people with mental health problems are excluded from the workplace and from key parts of society - this can be degrading and humiliating. We believe that many lives are emptier and less fulfilling than they need be and that many people have a great deal of skill, knowledge and experience that is currently being wasted, or misdirected into menial and unfulfilling work. As well as the obvious pain and distress to individuals, we feel this amounts to a significant loss to society. These thoughts and interests have emerged from our own concerns and difficulties in trying to rebuild purposeful existence.

Most of the team are both participants (answering the questionnaire) **and** researchers. Like other user-led research projects supported and supervised by Strategies for Living, this work is part of a growing field where service users participate more fully in planning, researching, reviewing, designing and assessing services intended to help them. We believe that, by reflecting on our own experiences and those of others like us, we can learn a lot, and that this learning is as credible and relevant as other types of research. This way of doing research also contributes to the shift away from believing that health professionals and those with power have all the answers, to a position where people value their own experience, can find out what is best for them and make active choices.

Aims of the research

Our research aimed to find out about the experiences of people who have lost an occupation following mental health problems. The questions we wanted to answer were:

- What is the importance of an occupation in people's lives and are identity, meaning and purpose in life connected to having an occupation?
- What is the impact of losing an occupation? How does this loss affect identity, self-esteem and confidence?
- How does stigma affect people?
- How do people re-form their lives after these experiences of loss?
- If people have found a new occupation, what helped them, and what got in the way?
- What do people's stories tell us?

Our assumption has been that occupation is important in people's lives and that there is often insufficient emphasis on this area. One of our objectives, therefore, is that the research should encourage better information and services for people with mental health problems who want to rebuild their lives and regain meaningful activities and occupation. We hope our work will help to shape and inform services that will meet people's needs and expectations more effectively.

We hope to find ways of disseminating this work creatively. We aim to connect with health professionals, and other local service providers in Bristol and to seek involvement in planning and developing new services. We hope to be able to get service users involved in training health and social service professionals to support a process of change, and to influence changes in the benefits system and employment conditions.

Methodology

We planned to do the research in two phases. First via a self-completion questionnaire exploring a wide range of issues around occupation and mental health. We designed a questionnaire to involve a fairly large number of people, to test out our ideas, and identify important themes. The second phase of the research selected a few individuals to take part in semi-structured interviews. In the interviews we wanted to gain in-depth information so as to provide individual case studies which would enrich our study.

The questionnaire we created was fifteen pages long, and included both quantitative and qualitative questions. The qualitative questions encouraged people to comment in their own words and tell us their stories. All the questions and statistics on the quantitative data are in Appendix 1. We aimed at a wide distribution in order to receive a total of 50 completed questionnaires. We publicised the study through the service user network in Bristol, at a number of meetings and conferences, and through other mental health organisations. We informed local mental health teams so they could put up flyers about the project. We also sought to broaden participation by advertising on shop notice boards, in GP's surgeries, on the Strategies for Living website, and in the local press.

From the interest we received we sent out 90 information packs and received 56 completed questionnaires: a 62% response rate.

We did not aim to generate a representative sample of people. Indeed we are doubtful whether such a sample could be accurately identified given that the stigma attached to losing work due to mental health problems means that much information remains hidden. Instead we sought the responses of people who identified with the issues we raised, and felt strongly enough about them to make the effort to complete a complex questionnaire.

Our quantitative findings, particularly when the sample is broken down, are based on small numbers. We have used them to generate charts and descriptive findings rather than focus on statistical analysis.

Chart 1: Age range of Sample

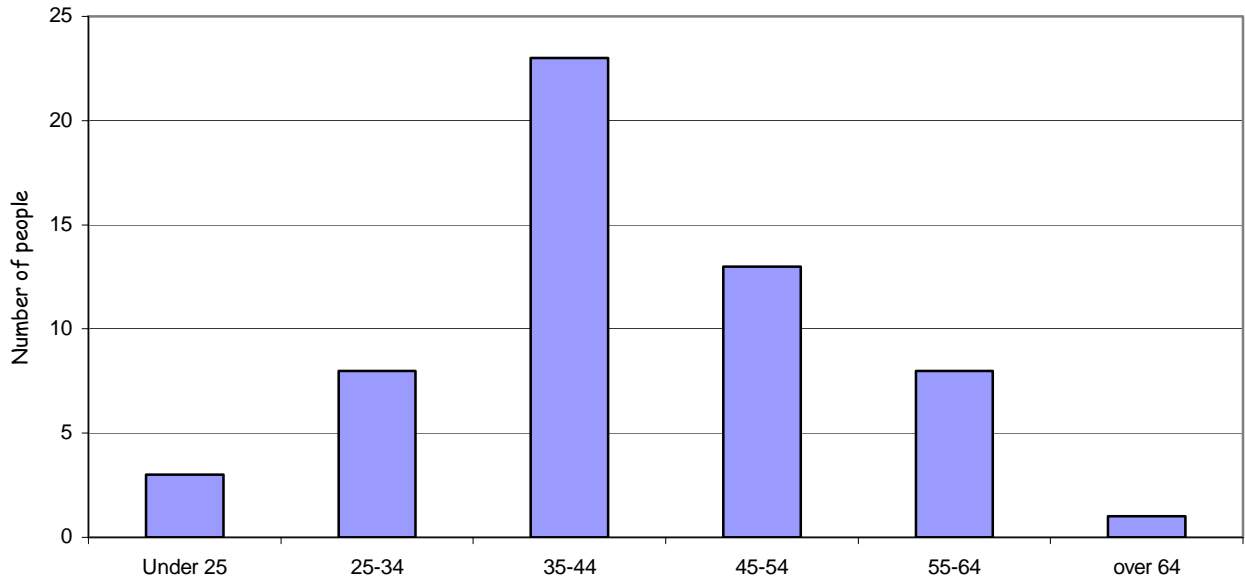
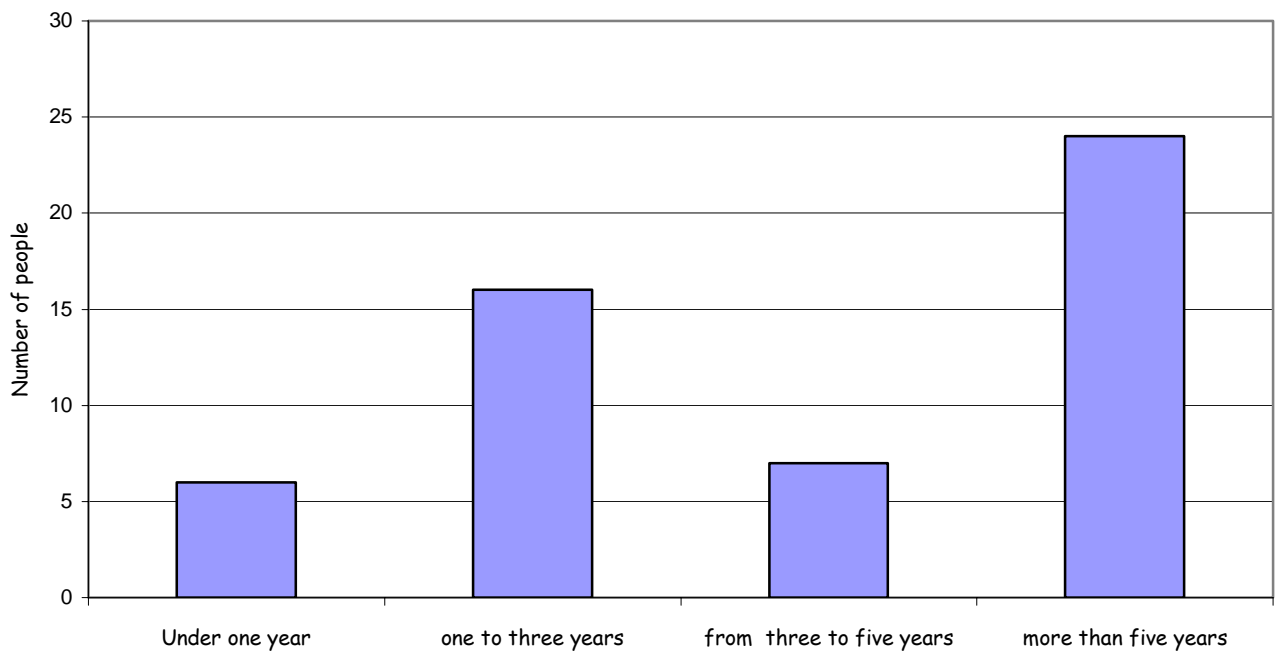


Chart 2 : Years since leaving occupation



The majority of our respondents came from Bristol and the surrounding areas, but some came from further a field:

- 66% of our respondents were in skilled or professional occupations before they lost their work
- 42% worked in education and caring professions
- 66% were women
- the overwhelming majority were white: 2 people described themselves as mixed race; 2 as Jewish.

We asked everyone who filled in the questionnaire whether they would like to take part in an in-depth interview and whether they would like to receive information about the research findings. Following two pilot interviews, we chose six local people to interview whose responses linked with themes emerging from the questionnaire. However, in the end, we only did three interviews. The questionnaire phase took longer than expected and generated a huge amount of data to analyse. This shifted the emphasis of the study.

Interviewees received a letter, information sheet and consent form. We paid people £10 to take part in the interview and also covered travelling expenses. We gave people a pack of information after the interview including contact details for support services, information about local services relating to occupation, and a thank you card.

After the interviews the full typed transcripts were sent out to interviewees. We also sent them a draft copy of their case study to comment on before publication.

We were aware that participating in this research might be painful. At least one person could not finish the questionnaire because the issues raised were too raw. In the interviews we flagged up this possibility in advance and suggested people think about their support needs. We also made sure that we finished on a positive note.

Findings

The Impact of Loss

The significance of work is demonstrated by how respondents regarded their previous occupation: almost half reported that they found their job enjoyable and contributed to a sense of who they were. Furthermore, a majority found their job stimulating and meaningful. They were also aware of the constraints imposed by work, particularly the amount of time it consumed. However, some did not enjoy their work and thought their last job had damaged their confidence and contributed to their mental health problems.

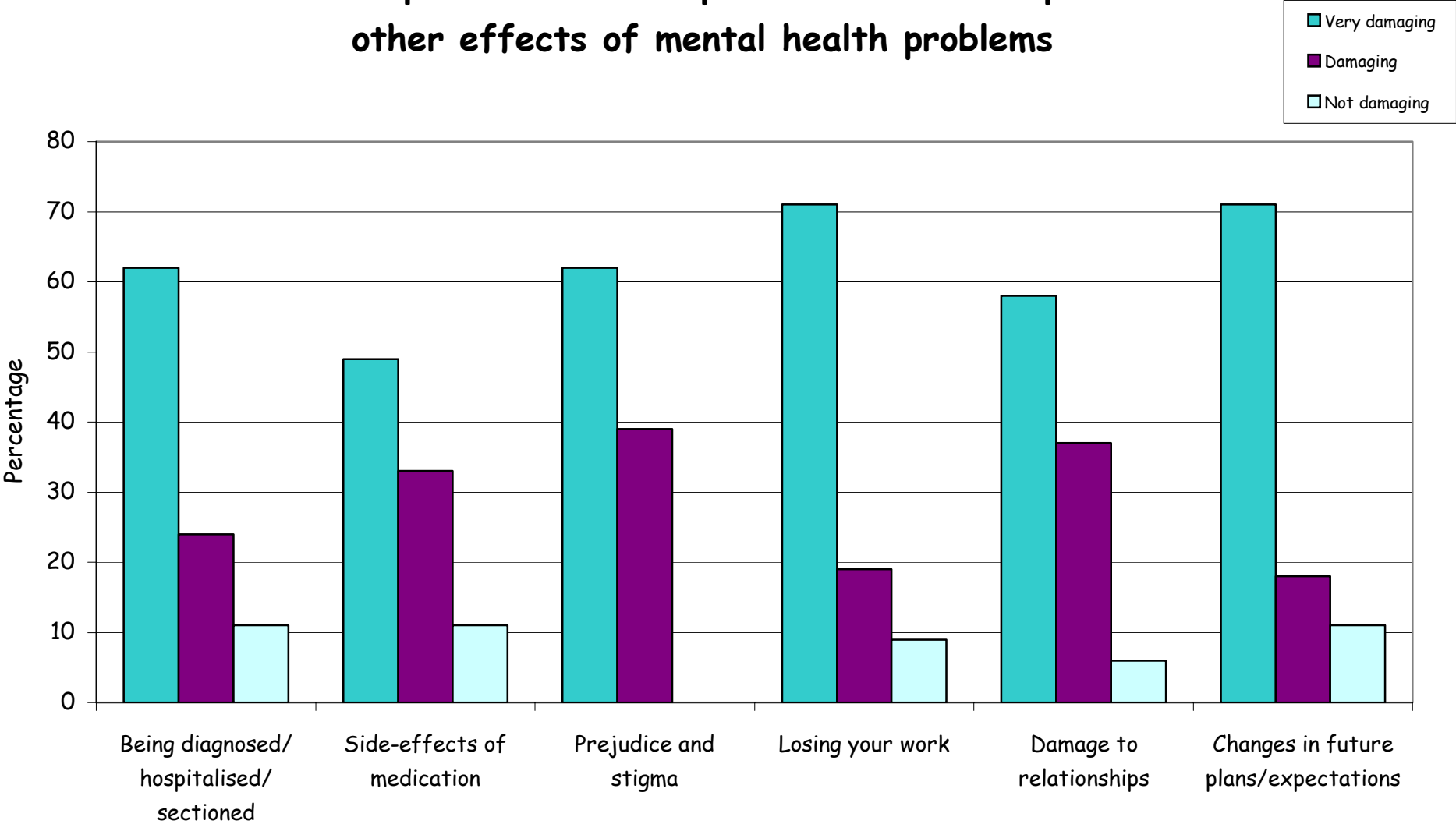
We asked a number of questions about previous occupation. When looked at together three groups emerged: 22 people (39%) rated previous work positively, 18 people (32%) neutrally and 15 people (27%) negatively. The negative group tended to report their previous occupation as being relatively unpleasant, boring, bad for confidence and meaningless.

Of the 56 people in our sample 37 had skilled work, including 12 people in teaching, lecturing and training; and eight in social services, housing and support roles. 15 people had been in semi-skilled work.

- **We can see from Chart 3 (over the page) that loss of occupation was rated as one of the most significant aspects of mental health problems.**

The process by which many people left their jobs was not straightforward: 13 people reported that they left voluntarily, and 9 felt too embarrassed to return after being unwell. Another 15 said that they were either asked to leave or encouraged to resign. A number of people were either retired early, made redundant or did not have their contracts renewed. Stigma played a major part in people losing their jobs and in preventing a successful return to work. *"I tried to return but found it difficult 'to fit in'; everyone knew, I felt quite stigmatised."*

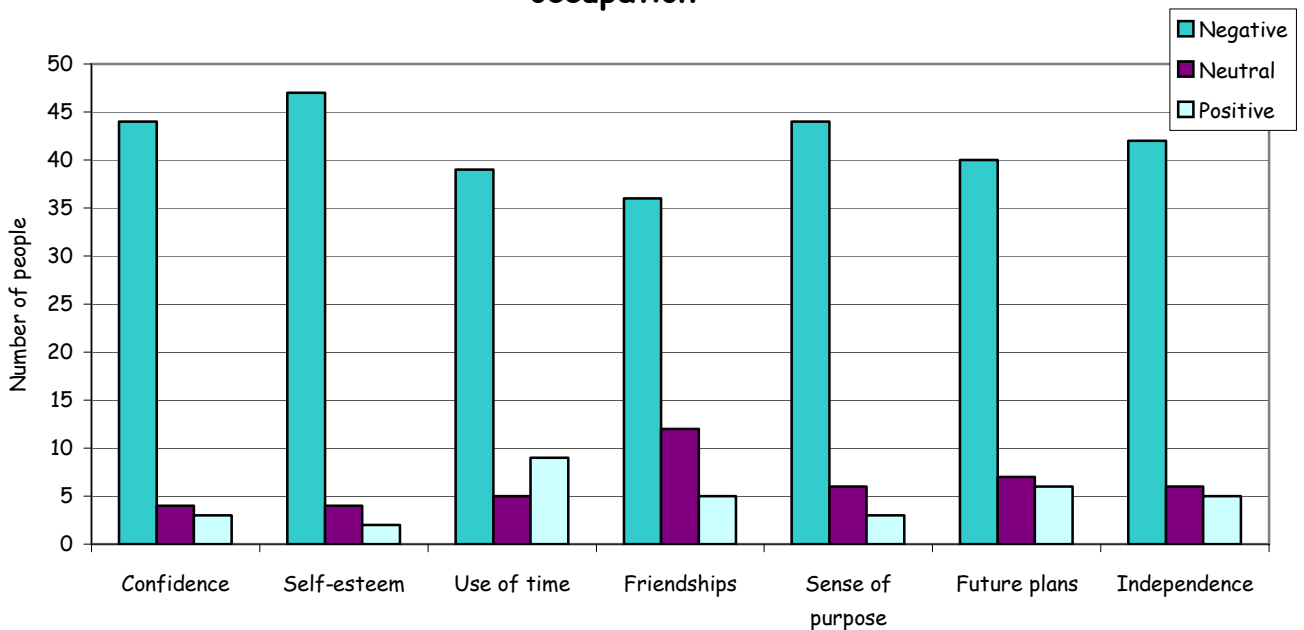
Chart 3: Comparison of the impact of loss of occupation with other effects of mental health problems



Loss of occupation was almost overwhelmingly a negative experience as can be seen in Chart 4.

Not only did confidence and self-esteem suffer but future plans and ambitions and people's sense of independence were damaged. Sense of purpose was also seriously affected. Even those who had generally had a low regard for their job felt strong feelings of loss.

Chart 4: Negative, neutral and positive effects of loss of occupation



The traumatic, and often long-term, effects of losing work are illustrated by the comments people made about their experience. One person wrote *"losing my occupation was the worst thing that has happened to me in my life apart from my separation/divorce"*. Another felt his life was shattered, *"my job was my life, I felt my life was destroyed"*. For almost everyone it was a major blow even if they had left their occupation 'voluntarily'.

Poor management and lack of support, as well the stresses and conditions of the job itself, were mentioned as factors that had led to deterioration in mental health and inability to continue working.

The deep sense of loss and the time and steps taken to deal with the experience was likened by one person to a process of grieving, *"initially I felt quite euphoric and confident, and only realized the real effects some time later (later on in the grieving process) which were that I felt very hopeless and completely without direction. I had relied too much on my job to boost my fragile self-esteem"*.

The negative feelings could be very pervasive. For some, loss of work also brought home the major part it had played in their lives. People felt the loss of status and role and connection to society. *"My teaching work was a vocation, for which I trained 5 years. Losing work which has seemed "meant to be" is very confusing."*

A few looked back on the effects of losing their job as either positive or mixed. *"If I hadn't lost my occupation I'd have ended up dead. So hard to weigh up the loss of teaching as a possible lifetime occupation against being alive."*

The experience of losing work was made much worse because it resulted in social isolation and significant damage to relationships. These findings are described in the section on stigma.

- **31 people (55%) reported that they had unsuccessfully attempted to return to work or study - many several times.**

Subsequent attempts to return to work often reinforced the debilitating effects of the original loss. They further undermined confidence, and heightened the sense of failure. *"Not being able to be reliable and meet commitments is very demoralizing. The loss of confidence makes me reluctant to venture forth"*.

Taking on voluntary work could also be a testing experience and lack of success here led some to feeling a sense of hopelessness. *"When voluntary work failed, confidence plummeted. When study failed ... there was no hope for me"*.

Some comments suggest that people tried to return to work too soon, perhaps underestimating the difficulties involved or their own limits: *"Embarked on some (work) too early to satisfy others and paid a high price knocking back confidence and self esteem"*.

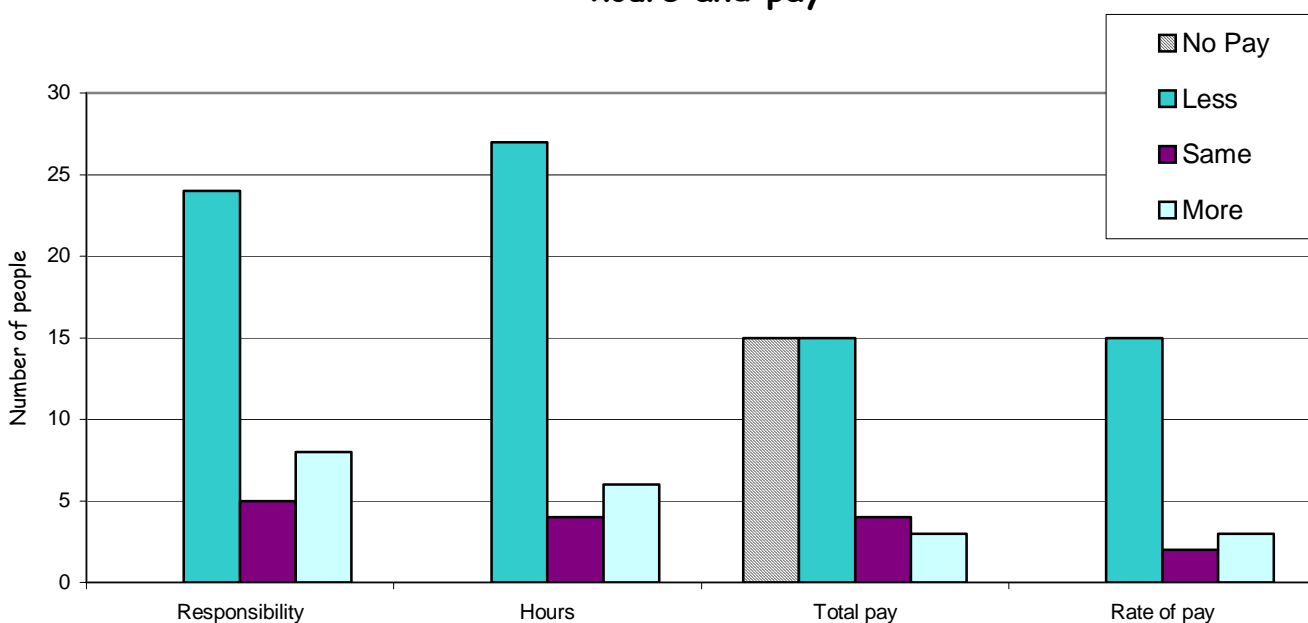
Despite these setbacks, many made repeated attempts to work. *"The last attempt seems more successful. I am not cracking up yet, I think"*.

Some chose to give up to avoid stressful situations: *"the last time I gave up work because of mental ill health - 5 years ago- the decision made me feel better about myself because I felt I had more control over my life. I have grown in confidence because I have avoided consistent stress which was causing / triggering my illness"*.

- **32% of people in our study had no current occupation.**

68% had some kind of occupation when they filled in the questionnaire, but the vast majority had less responsibility, worked less hours and were either unpaid or paid much less. This is illustrated in Chart 5 below. Nonetheless, those who had a current occupation tended to value it highly, but people who were most satisfied with their previous work tended to be least satisfied with their current occupation.

Chart 5: Change from previous to current levels of responsibility, hours and pay



- **31% of people felt that their sense of who they were had changed for the worse as a result of losing occupation.**

This group reported very painful and negative feelings and an ongoing sense of loss. In comparison to the whole sample, this sub-group had a higher proportion of people that have been out of work for one to three years, and relatively fewer people out of work for more than 5 years. These people could be described as currently being 'stuck' in loss. The reasons given included a sense of failure and inadequacy, loss of identity, confidence and self-esteem, loss of status, power and skills, lack of purpose, inability to concentrate and loss of energy. One person reflected how not working led them to "self-obsess" and live in the past. Another felt trapped with a sense of fear, adding, "life has become pure endurance. I was confident and enjoyed life, now I hate myself and enjoy nothing".

- **A quarter of respondents commented on the loss of income.**

"As I am paid a lot less I find it quite hard to get by financially ...". "I am now very short of money and find it difficult to maintain my house". "I think money is more important now that I am on benefits". "Impossible to survive on £50 a week" "Student debt and hardship was a very big contributing factor"(to illness). "I am running out of money and extremely worried and stressed"

One response reflected the feelings of many:

"My work was an ongoing self-development programme. Without it, I have no idea in which direction to go, so I am just stuck - becalmed but not calm - frustrated. I don't like not working, but I don't feel ready or able to venture out into the 'real world' yet".

The Effects on Identity

- **Confidence and self-esteem were damaged by loss of occupation.**

We have already seen how people's confidence and self-esteem were damaged by the loss of an occupation. Charts 3 and 4 (pages 8 and 9) in the previous section show how negatively people's future plans and ambitions were affected. This reflects how people's expectations were damaged with obvious impact on their identity.

There was strong evidence that, over time, loss of occupation and being unwell had led to a re-evaluation of attitudes and priorities among many of the respondents. These changes of approach reflected shifting values and changes to identity.

- **For many work was no longer seen as an end in itself.**

Work needed to be meaningful and supportive to mental health (which led a few to work in the field of mental health). *"Work used to be the most important/central thing in my life. Now I try not to let it be, though it is still vital for me to have something meaningful to do."* *"Having a full-time well paid job is not important, I focus instead on how it helps maintain my well being".* *"Work does not need to define me as it did in the past".*

- **Having the right approach to work was emphasized, understanding personal limits and getting the work/life balance right.**

"It is not what you do but how you approach it." *"Plan work around being able to take time off."* *"Becoming more focussed about what I want out of life, what makes me happy, satisfied, interested and less anxious/stressed."* *"Balanced lifestyle very important."* *"Important to have a balance between work/leisure so that life is not too work oriented."* *"Can't let work rule your life".*

Many saw work as a way of maintaining confidence, routine, social contact and self-esteem. *"Important for self-esteem, confidence and a place in society."* *"Work is very important for involvement with others".* *"Important to keep busy and do something useful even if not for money".*

For others work was still crucial to their identity. *"Work is central to my life; I see my identity as worker, independent and self sufficient".* *"I realised since I gave up teaching that we are defined by what we do".* *"... I fall apart without occupation".*

- **Social relationships had become more important for many.**

"Very important to look at support networks for sharing experiences and forgetting about things." *"Close supportive friends very important."* *"Made me more conscious of the need*

for friends and the importance of making time for people and relationships". "Having time to spend with family and friends seems much more important to me now".

Some gave increased value to leisure, although others did not find it enjoyable without a structure, company or money. *"Have more leisure time which I value." "Find it difficult to enjoy myself on my own." "Can't organise activities/think of what I could possibly enjoy." "Get frustrated at financial restrictions."*

➤ **Our respondents also reported changing attitudes to money.**

For some their experiences led to financial difficulties and loss of independence and respect. *"Poverty is a stress in itself. There are so many things you miss out on not having enough money i.e. food, social life, holidays, comfort". "The most major loss has been financial independence. I have had to move back in with my parents and am now reliant on them financially". "It feels much better if it is earned rather than doled out".*

For others money became less important. *"Money is nothing if you are miserable". "Doing something meaningful and enjoyable is far more important than earning a living"* and someone else stated that money is *"not as important as being confident and happy"*.

➤ **Without an occupation there were serious difficulties in finding any purpose in life.**

We asked whether losing an occupation had affected our respondents' approach to purpose in life. Some reported that occupation was very important in having a sense of purpose. *"I feel better now that I have a job I enjoy and colleagues I get on with." "I have been without purpose at times. My job gave me a feeling of contributing to society."*

Others described their difficulties. *"I thought I knew what I want to do work-wise, but now wonder if it is too stressful for me. So I wonder what else is there and what else could I do." "I need a goal to keep myself from going under". "I can't enjoy anything, I don't know what to do. Desperate." "Still no real purpose in my life."*

However, others felt that their experiences had been liberating and enabled them to make their own choices and find a more satisfying way of life. *"Strangely I feel happy that my madness has taken me out of the rat race and given me a chance to learn a lot more about power/reality/spirituality/social relations/compassion." "There is more to life than trying to achieve, to be the best in a fast, stressful work environment." "I now aim to do what I believe in and not to follow society's expectations"*.

➤ **Some felt positive about their new lives.**

Many sought to have more of a purpose by helping others; some had adopted a more philosophical or spiritual approach, seeking to *"... find purpose in everyday things rather*

than far off plans." "Sometimes it's enough just to be". "I try to do some things to help others ..." "Helping others in similar condition ... is very rewarding".

We also asked whether people's sense of themselves had changed as a result of loss of occupation.

- **For the 31% who felt changed for the worse, loss of status and role in society had a very negative impact on identity.**

"I used to live and work to support my wife and children, now I don't seem to have a reason for living." "I was a qualified professional worker plus wife and mother, now I am only a mother." "When I got that job I felt as if things were coming together for me and I'd found a worthwhile and reasonably well paid job. Now I wonder if I have to accept I can only do low-level low paid work".

Many of this group reported feeling a failure, stupid and inadequate. *"I cannot use the 'skills' I used in teaching so I see myself as having failed in life". "I still have problems feeling stupid or inadequate" "I feel worthless, a failure, lost ... trapped, no way out".*

- **45% of people said that their sense of self had changed for the better as a result of their experiences.**

"When I was teaching I felt that I had to pretend that things were OK when they weren't. I feel able just to be myself in my present occupation". "It meant I changed my direction and found a more fulfilling job which changed my sense of who I am radically". "I think I am more understanding of others problems." "It forced me to take stock of my life and to be honest/realistic about the pressures I could live with ... I now feel I know myself a lot better". "I suspect if I hadn't become ill I probably wouldn't have my daughter but only a successful career".

- **Nonetheless, answering the question 'What do you do?' remained deeply distressing for most people. As society values occupation as a key part of identity, our respondents highlighted a serious vulnerability in this area.**

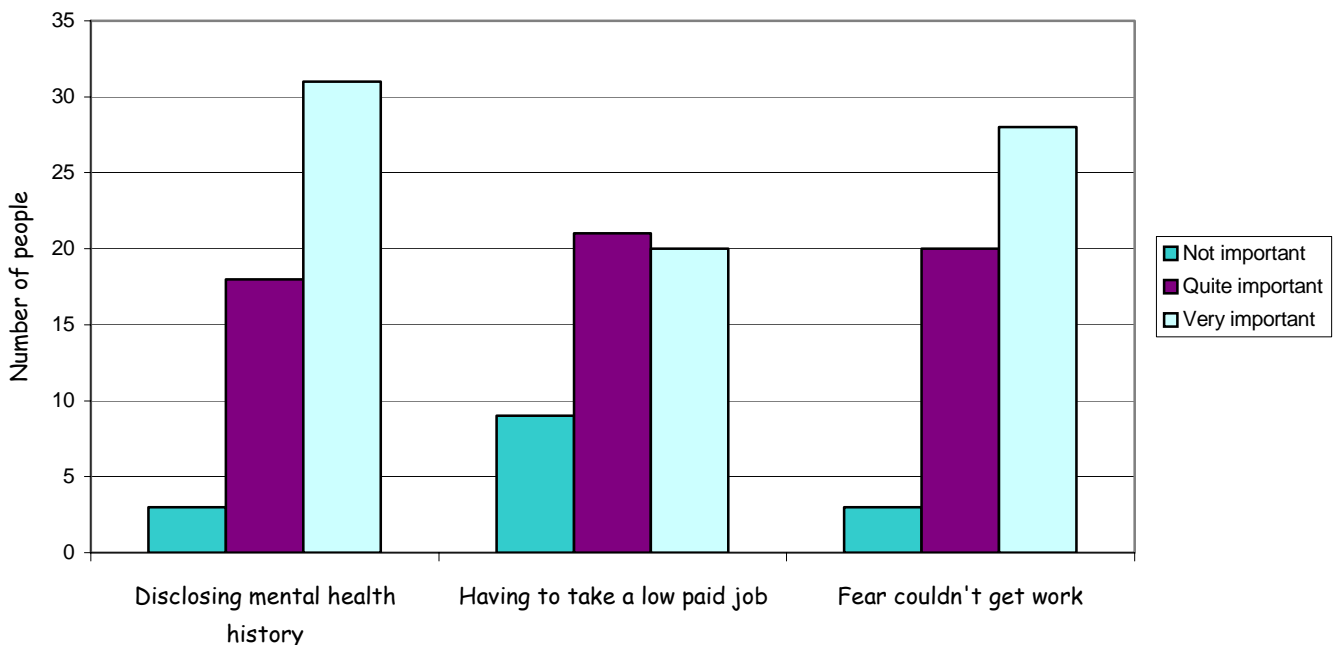
Thirty-one (55%) people felt negative about answering this question, many very negative indeed. Most people felt ashamed and embarrassed, some felt defensive and angry, others fearful and upset. See pages 20-21 in the section on the Effects of Stigma for more information.

The Effects of Stigma

- When asked about the relative importance of different aspects of mental health problems, there was one unanimous response. Everyone who answered the questionnaire felt damaged by stigma and prejudice.

Stigma strikes at every stage: it can cause the loss of occupation, it affects people trying to regain work. It also affects people without work as seen later in this section. Nine people gave stigma - being too embarrassed to return - as the main reason for losing their work. Five others mentioned embarrassment as a reason for leaving work. *"I felt I had little choice ... would have felt vulnerable had I returned."* *"Harassed over repeated absences."* Thirteen people left voluntarily, but sometimes this was also linked to stigma *"left voluntarily but felt I had little choice and would have been vulnerable had I returned"*.

Chart 6: Stigma issues in taking up work again



We asked people to rate a list of issues related to taking up an occupation again. Three of them (shown in Chart 6) were potential barriers that connect to stigma. Nearly 50 people saw disclosing mental health history as important, which indicated potentially both fear of discrimination when seeking occupation and fear of negative reactions from others if they 'disclosed' in the workplace. Over 45 people report related fears about whether they would be able to get work. Having to take low paid work was also a significant concern.

32% of people in our study had no current occupation when they answered the questionnaire. 68% had some kind of occupation, but the vast majority had less

responsibility and were either unpaid or paid much less (see Chart 5 on page 11). While this may reflect some people's changed priorities it may also reflect serious discrimination. *"I have been unable to return to work ... since harassment etc. very low confidence and self esteem"*.

- **People's skill and experience seemed to become invisible and expectations were very low.**

When asked whether others see them differently, some people commented that they felt stigmatised by health professionals who did not acknowledge their skills and previous experience and had low expectations of them. *"I felt they never had any idea that I might have previously had a responsible job that I did well". "I think I'm seen more as a hopeless case (by psychiatrist)". "I was told by consultants and nurses that I could apply for jobs but it was only for interview practice. Told I couldn't work again, especially in social work."*

As well as finding some health professionals stigmatising, there were comments about the need for mental health education for employers and employees. You need the *"support of a boss without fear of losing your occupation"*.

One person's comment reflected a common experience of low expectations regarding work. *"Experience of return to work guidance and training schemes is that they are geared for people with little or no further education background, therefore expectations are low and that doesn't help morale or self-esteem"*. Another commented *"an awful person .. 'helped' me write a CV which ignored all my qualifications and experience"*.

- **Our study shows that stigma creates social exclusion and damages relationships.**

Our respondents reported serious social exclusion. *"I have found it very difficult to return to the school where I taught, I felt very negative about my daughter starting school and hated going into her class"*. Problems can last many years; *"past colleagues still cross the street when they see me coming (14 years later)"*. People who live in small communities, or were in positions of respect, seemed to feel the shame more acutely. *"I worked within a small community. Every time I went out I would meet people I worked with. Sometimes I would have weeks where I wouldn't leave the house because of this"*. People felt ignored, talked about, or felt that they had to hide their problems from their neighbours. *"I kept my illness well hidden here - I've seen their reactions to others"*. *"They tend to ignore me"*. *"They gossip and thought I was mad"*.

Five people reported that they had split up with a partner. Others felt their partners saw them as less important and felt less respected since they had lost their occupation. Only two people commented positively about being understood, or that a partner had coped with the situation.

Twenty six people commented about the views of other family members: five of these comments were positive, reporting understanding and support; however the rest were negative. People reported low expectations from others, lack of respect and understanding, being seen as a failure, weak, lazy, incapable and as a disappointment. *"They don't respect my views or take me seriously". "My father gives the impression that he feels that I've failed in some way and that I'm just faking/lazy etc"*.

There were some positive comments about friendships being resilient; *"I'm closer to them, now I talk to them about how I feel without scaring them away"*. However, the majority of the comments about friendships were negative: reporting lost friends, lack of understanding; and even having to move away. *"All disappeared"*. Loss of occupation has *"affected my relationships terribly"*. *"I had to move away to find new friends"*. *"I feel a non-person, as if I'm no longer valid"*. Several people also commented on the loss of colleagues and friends from work. Ex-colleagues *"see me as a failure and idle and unable to work"*. *"My work relationships were very special and I miss them more than I would have realised"*.

Many people commented on the difficulty of having social relationships and some of these problems were linked to stigma. *"They are important and needed. A great deal harder to make now because of history and stigma. Would rather be on my own though if relationships are not right."* *"I am now anxious and reluctant in social relationships, I lack motivation"*. *"Medication and stigma at illness makes others apprehensive and cautious about me"*. *"Rebuilding damaged relationships has been very hard"*.

➤ **70% of people avoided people, places or situations connected to lost work**

Feelings of embarrassment and shame predominate, and once again this leads to isolation. Going back also brought back bad memories, was upsetting, and it was seen as hard to talk to people who did not know what had happened. Some people felt very angry about how they had been treated and the lack of support and understanding from colleagues or managers. Others feared being seen as a failure. Feelings were very acute. *"I have made a complete fool of myself"*. *"I eventually left the area and settled 10 miles away before I felt free of the stigma/discomfort of others and myself over what had happened"*. *"I have no contact with any of the people I worked with and to be honest I don't want any either"*. *"I am 'scared' to go to the local supermarket in case I meet people from my working life"*. *"They don't want to be seen with someone who has a mental illness. I avoided leaving home for several months"*.

Even among the 25% who did not avoid places, people or situations connected to lost work sometimes this was because they were no longer in the area. One person commented *"I have not been invited to a single event at which this might occur"*.

We saw in the section on Identity (page 15) that many people suffer from a loss of status and role because of lost work. People also lack a solid connection to society. *"As a single*

person with no family or children teaching gave me a sense of belonging. I now feel isolated and not really part of society".

➤ **Most people felt very negative about the question 'What do you do?'**

More than half felt negative, most very negative indeed. Sixteen people felt ashamed, embarrassed, awkward, apologetic or uncomfortable. Eight people felt defensive, threatened, angry, insulted or violated. Six people felt nervous, anxious, panicky, upset or vulnerable. Four people felt unsure of what to say or reticent. Fourteen people felt OK about this question, but most of their responses were quite neutral, only a couple of people said they felt positive about talking about what they do.

"I positively dread it ..." *"Sometimes I get so cheesed off my reply is - I'm a professional nutter."* *"Not sure what to say, how honest to be."* *"I always feel awkward about this - its quite painful".* *"It's very threatening until I remind myself just because I don't have a job doesn't make me a nobody."* *"I have to cling to my former status."* *"Get panicky in case they delve too deep and ask too many questions."* *"Like a fraud."* *"I would feel ashamed and guilty".*

There was one very striking response:

"I don't like it. Because I feel I do nothing and therefore don't deserve to eat or live."

What Participants found Helpful and Unhelpful

➤ People clearly wanted and valued occupation.

38 people in our study (68%) described themselves as having a current occupation²; 18 people had paid work, 23 people had voluntary work and 14 people were studying; 11 people were doing two of these options, 3 were doing all three.

23 of the people with current occupation (60%) rated it as better overall than their previous work. Just over 30% (12 people) rated their current occupation as the same as their previous work and under 8% (3 people) rated it worse. If people had an occupation they tended to be satisfied with it. In particular, current occupations were rated as being better for mental health and confidence, and as less stressful, see Chart 7 (p. 23).

Nonetheless, it seems significant that the people who were most satisfied with their previous occupation were least satisfied with their current occupation.

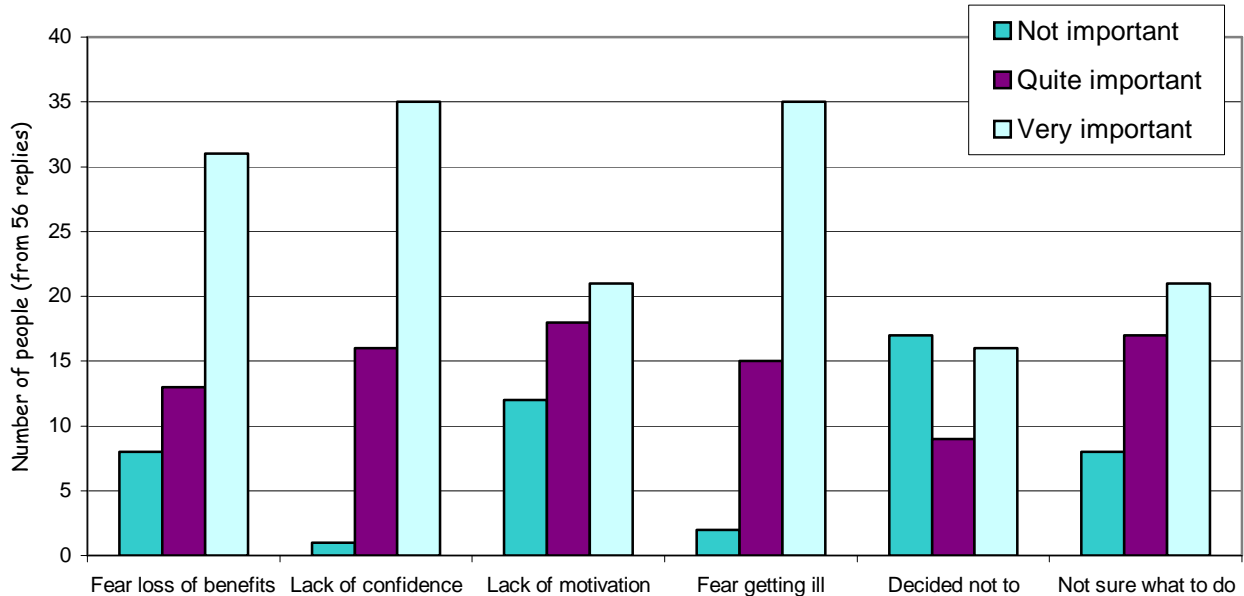
Of the people with no current occupation (32% of the whole sample) most (78% of this sub group) wanted more occupation. We asked this group of people how the activities they did affected their confidence, sense of purpose, contact with others, self-esteem and mental health. Around 80% of the group felt their activities did improve their confidence, mental health and social contact; fewer (65%) felt activities affected their sense of purpose positively. Most satisfaction was gained from a hobby or interest or from caring for others. Other useful activities included meditation and worship, campaigning and chatting on the Internet. However, there were a significant number who felt activities did not help their sense of purpose, mental health or self-esteem.

➤ People perceived significant barriers to regaining occupation.

All the factors that we listed as potential issues in taking up occupation again were seen as very or quite important to the vast majority of people; getting another occupation was perceived as a difficult and stressful process, see Chart 8 on page 24. The **most** important factors were lack of confidence, fear of getting ill again, and fear of loss of benefits. Other factors were described under Stigma (see Chart 6 on page 17). Together these factors amount to very significant barriers to regaining occupation.

¹ We define occupation as doing some kind of paid or voluntary work (however few hours) or study.

Chart 8: How people rated the importance of issues about taking up work again



We asked people what they thought were the **top three** priorities for helping people to find meaningful occupation following mental health problems.

- **Thirty-four people (61%) prioritised issues that broadly focus on the need for support; this makes provision of support the top priority. People wanted both general support and encouragement and support in specific areas.**

People identified that support was needed to:

- Help them understand and cope with their mental health problems, including the causes of these problems and with the prevention of further illness.
- Help to re-establish an 'ordinary' life.
- Find activities and occupation.
- Try things and help to regain some self-esteem and confidence.
- Help them feel they can have a future that includes some kind of occupation despite having a mental health problem.

Support includes emotional support and the need for talking therapies. People also wanted practical support to help them negotiate the stresses of going back to work.

- **They wanted support that is regular and ongoing.**

"Chance to work with a 'coach' who can look at your whole lifestyle." "More talking therapies available, alongside any assistance to obtain occupation." "Help and support to find meaningful and structured day time activity." "Support to solve problems that caused mental health problems." "Having support available to prevent further illness." "Ongoing practical and emotional support to negotiate stresses of going back to work / study, especially full time."

- **Another sixteen people (29%) wrote about the need for appropriate guidance, advice and information in order to find a suitable occupation.**

These people wanted help to identify their aptitudes, to explore possibilities, to identify realistic and achievable goals, and to find out what is meaningful and enjoyable for them. They wanted help to identify and investigate career options and to find situations where they had a chance of succeeding. These priorities obviously overlap to some extent with other support needs, but can also be described as a separate theme.

"Professional advice (i.e. careers advice / benefits advice & job centre (that is) user friendly." "Help in identifying alternative career options." "The chance to explore ALL the possibilities with a skilled facilitator." "Information - on careers available and employment rights."

- **90% of people therefore prioritised support in some form.**

We asked the 38 people with a current occupation who helped them make the transition back to work or study:

- 21 people said family or friends had helped them
- 17 people said they had had help from health or care professionals
- Support groups had helped 16 people.

When asked to evaluate the help they received, 13 people rated the support given by family and/or friends as positive; six people rated it negatively. Twelve people rated the help of health or care professionals as positive; five as negative. Nine people rated support groups positively, five negatively.

Hardly anyone had had any help from the other possible sources we had identified - employment agencies, volunteer bureaux, previous employers, benefits agencies, occupational health services. The same number of people rated these sources as unhelpful as helpful.

- **Some people had found effective support, but not that many. Quite significant numbers of people found what was offered actively unhelpful and a lot of people had no help at all.**

- **When we asked people to tell us what had most helped them return to an occupation the most common responses were to do with people's own efforts and qualities.**

"My own motivation." "My own diligence and application." "Persistence in the face of repeated failure. Adaptability." "Determination to hang on in there." "Sheer bloody mindedness and curiosity." "The desire to contribute and be useful in some way." This shows an emphasis on people's own strengths and determination, not an acknowledgement of or reliance on support.

To their credit, 25 of the 31 people who had experienced several losses of occupation had gone on to find some kind of occupation that they find satisfying.

- **Nearly 80% of the people currently without occupation wanted more support to help them get involved in activities or an occupation.**
- **Twenty-two people (40%), the second largest group, prioritised issues around benefits and pay.**

Fourteen people prioritised a better benefits system. Seven of these comments focussed on a more flexible benefits system, particularly allowing for false starts, gradual recovery, and being able to go back on full benefits if you get ill again. Others focussed on the need for security, being able to work or train and get benefits, and on getting more information and advice about benefits.

"Provide flexible benefits system to fall back on." "A more flexible benefits system to allow people to re-enter work gradually." "Changes to benefit systems to allow for false starts / gradual recovery." "Being able to work without having to be signed off benefits." "Benefits, you should be able to go back on full benefits if you get ill again." "Benefits while retraining."

Eight people wrote about more general financial support including the need for good pay, financial incentives or help in getting back into an occupation, and clothing grants.

"Help financially / legally etc to ensure that people aren't penalised if their occupation is not well paid or if they are only able to achieve full time working sporadically." "Financial support so that part-time work is viable."

- **Fifteen people (27%) prioritised the need for better equal opportunities practices and stronger anti-discrimination laws for people with mental health problems, or expressed fears about discrimination and harassment.**

Comments included a few statements about the need to look at broader problems of class, race and structural inequalities.

"Measures to ensure that there is no discrimination by future employers." "Good equal opportunities policies." "Employers need education that people with MD (manic depression) can offer a great deal and should not be considered a burden." "Make it harder for employers to sack mentally ill people." "Fear being harassed / being low paid."

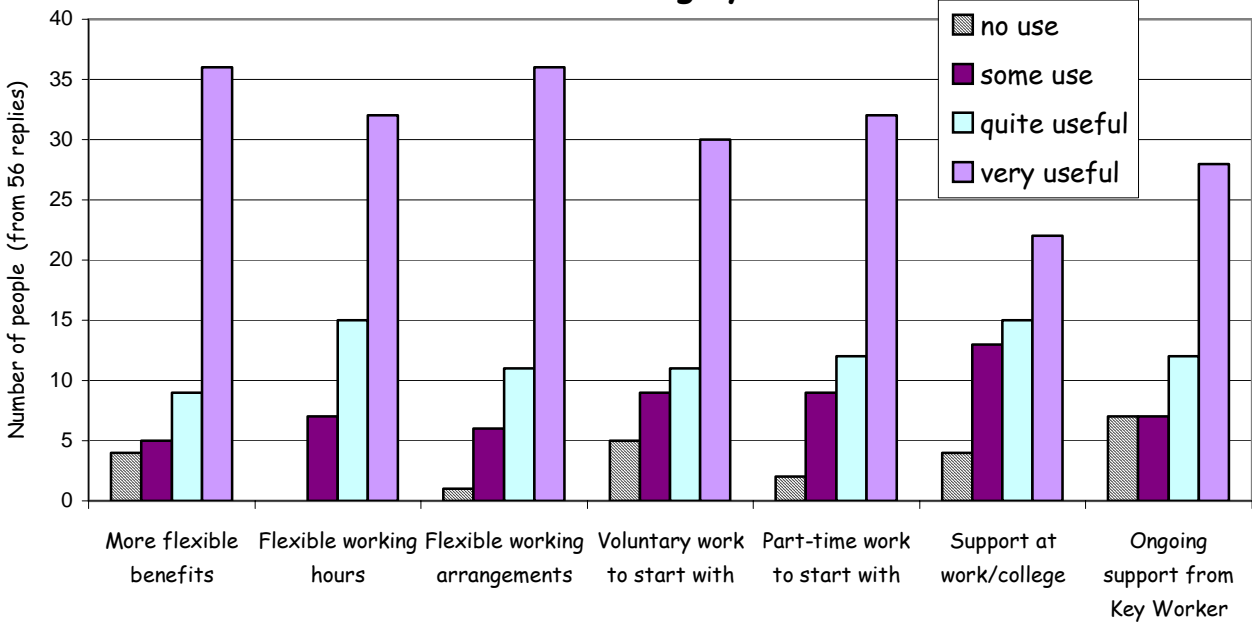
We asked everyone (with or without occupation) what kind of help or support was or could be useful for returning to an occupation.

See Charts 9 and 10 opposite.

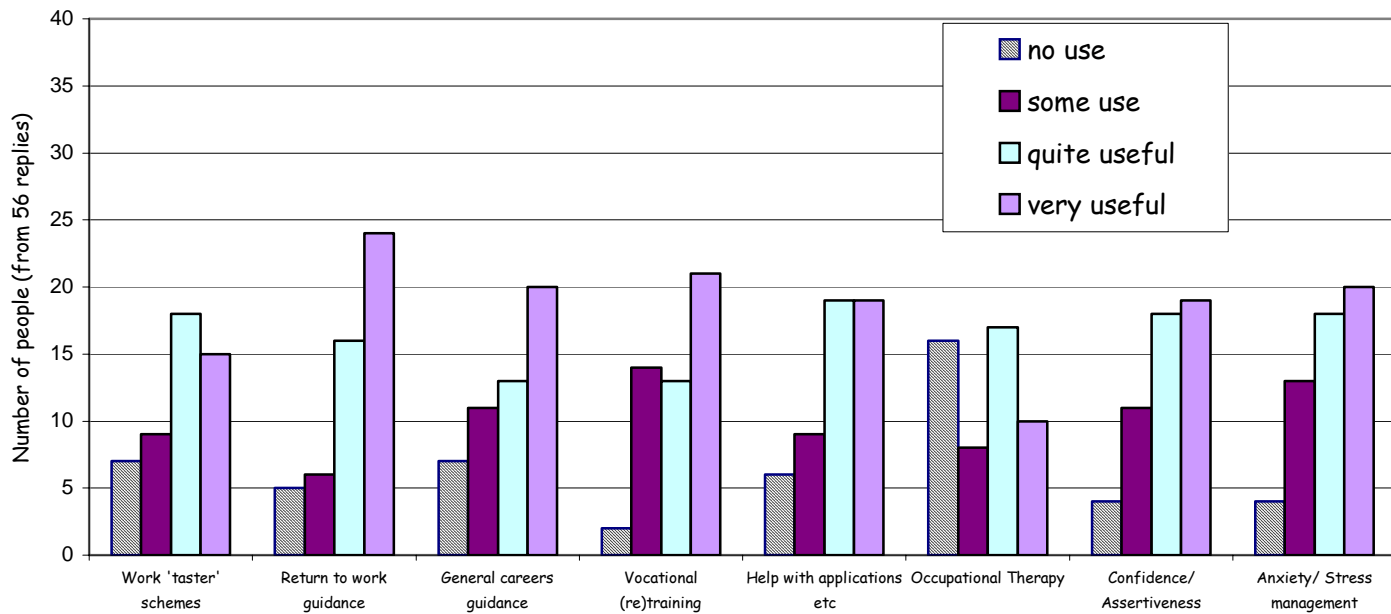
- **Most people rated the need for flexibility highest, wanting flexible working arrangements, flexible working hours and flexible benefits.**
- **Next highly rated were part time or voluntary work to start with.**
- **A lot of people also felt that ongoing support from a Key Worker would be helpful.**

The factors which were identified as least helpful in regaining an occupation were Occupational Therapy, work taster schemes and general careers guidance. However, quite a number of people still felt that these things might be quite useful. In fact most of the possible sources of help we identified were seen positively.

**Chart 9 : Factors helpful for returning to an occupation:
most highly rated**



**Chart 10 : Factors helpful for returning to an occupation:
less highly rated**



A number of the comments relating to this question focussed on the need for emotional support or therapy; so although the question asked what would help people return to an occupation, there was recognition that people need a more holistic approach. This reinforces similar findings described earlier.

Several people wrote about needing a supportive work environment and good working conditions. The wide range of additional suggestions made indicate that help needs to be tailored to people's individual needs, that one formula cannot be right for all.

Some people clearly felt beyond help:

"I don't think that I'll ever work again. It's been too long and no employer would look at me twice anyway".

A Journey without a Map

- **The stories people told us show that loss of occupation alongside mental health problems tends to push people into embarking on a long, unexpected and often painful journey into uncharted territory.**

As we have seen, people experience traumatic loss: independence, previous plans and expectations are severely damaged, as are confidence and self-esteem. Many people feel their experience has changed them for the worse and undermined their sense of purpose. Loss of status and role are accompanied by feelings of inadequacy and failure. Being asked 'what do you do' stimulates feelings of shame, fear and anger. Our respondents suffer from social isolation and damage to relationships as well as from other forms of stigma and discrimination. Most people avoid people, places and situations connected to lost work and many find it hard to live with little money. These experiences often trigger significant changes in identity.

Some people describe it as a journey through hell; *"loss of occupation has made me suicidal and unable to look into the future."* *"The early years were hell."* *"My confidence is totally shattered."* The journey obviously takes time, there are no quick fix solutions - 55% of people in our sample lost their work more than three years ago, 42% more than five years ago.

- **As they reflect back, people can see different stages**

They identify times when they were stuck in limbo and times of difficulty, anxiety or uncertainty. *"So far no clue as to which direction to take in the future. Feel in limbo."* *"Uncertainty of getting ill health retirement .. lead to being unable to plan until the outcome is clear".* *"Able to get into some voluntary work but anxious about what will happen in the next depression."* For some, a recognition that they have been able to move on. *"I would rather have not had the experience, but I can't change that. I can however use it to better myself and understand life more".* The journey is unlikely to be straightforward, there will probably be setbacks and adjustments will have to be made along the way. It is clear therefore that people's needs change over time.

- **People report that they have had to re-evaluate their lives.**

Most people describe significant changes to their values and attitudes regarding work, money, leisure, social relationships and purpose in life. Many of these changes reflect reduced emphasis on full-time work and money, and describe a different work/life balance. For some these adjustments feel positive reflecting personal growth and a more fulfilling life with less emphasis on the 'work ethic': *"I am actually discovering who I really am and meeting my needs rather than meeting everybody else's needs".*

For others their experiences continue to be painful and distressing reflecting an ongoing sense of loss and damage to identity: *"I feel stupid and thick and I can't concentrate and I feel unemployable. My identity was always tied to how I look and my intelligence, since I went crazy I am no longer able to use my brain for any length of time and the medication makes me fat."*

➤ **Each person's journey is unique.**

When reading people's stories it is clear that everyone has to find their own way through this difficult process, there are no simple and lasting answers. This suggests that services need to meet people where they are, not to try to fit them into 'boxes' which aim to accommodate all as if there were a 'standard' journey.

➤ **Our study seems to reveal two rather distinct groups**

One group report that loss of occupation changed their sense of self 'for the better', the other 'for the worse'. The 'for the better' group report a process of personal development and change, the discovery of different perspectives and new priorities which had led to the creation of a new, and often satisfying, life.

The 'for the worse' group report negative feelings of loss, inadequacy, frustration, isolation and failure. This group are more stuck, and much less satisfied.

Although people are unlikely to stay in one group for their whole journey, support is likely to be particularly important when people feel stuck and focussed on what they have lost. *"Life after being sectioned is very hard, it's better for animals. It's such a waste - to get out of a bottomless pit only to ... feel like lepers and on the scrap heap"*.

However, the journey has often taken people to an ambivalent place. A summary of one person's journey goes as follows:

I was living with mental health problems that were unacknowledged and with an eating disorder. I was also bullied at work, which led to depression and destruction of self-belief. In losing the job I admitted problems. I used to try to be like others, now I am learning to be myself. I need reassurance; I am scared of getting ill and doubtful of my own strength. Although my current voluntary work is below my intellectual abilities this is progress from stuffing envelopes two hours a week. It has taken 2-3 years therapy to get a bit more confidence and develop some self-respect. She finishes: *"Losing work made me confront issues which I was running away from. BUT is it enough to be 'me' where people are largely defined by their occupation?"*

Our case studies describe three participant's stories. We have changed their names to protect their identities.

Case Study - Emily

Emily is a young woman who had to leave her university course because of mental health problems. She had also been ill during her 'A' levels. As well as exam stress other things made her vulnerable: she is dyslexic and felt the need to prove that she could do academic work, she had had family problems and been assaulted. Having dropped out she got very involved with the Labour Party and then became a full-time officer for the National Union of Students. She resumed her studies on a part-time basis and graduated with a 2:1. More recently she met a new partner and found full-time work.

Emily really liked her university course. Being a student was her identity; when she lost this label she felt invalid, a failure and blamed herself for dropping out. It has been a long and difficult process to accept the mental ill health label and to make the necessary life changes. Her experiences have transformed her identity, altering how she thinks about herself, what she does and how she relates to other people. Campaigning against discrimination is now very important to her.

Although Emily is confident in some ways, she struggles over how much she should be *"wrapped in cotton wool"*. She is cautious about getting involved in new projects and this lowers her self-esteem; then she beats herself up for not getting on with things. *"It can be a lose-lose situation"*. At the same time she feels driven to take on a lot to show that she is capable and valuable.

She has faced discrimination - after being offered a job the health checks took three months. Emily was angry because she had the necessary qualifications and experience. She threatened the employer with tribunal action and managed to get some compensation, but she still feels demoralised by the experience. Emily has decided to be very open about her diagnosis. Not hiding it has increased her confidence but it is painful if people do not respond well.

Relationships have been affected in different ways. It was frightening and "too much" for some people when she was ill - some of these relationships are now repaired. Other friends were very supportive. Her father thought her illness was 'just a phase' and that she'd grow out of it; Emily still feels he doesn't really understand. Her mother has been more sympathetic.

Emily feels her self-esteem is much higher now she is in work and doing something worthwhile. However, she is not particularly happy in her job. Working practices and hours are inflexible and this is frustrating. She has appointments with health professionals and taking time out feels difficult. It would be good for her to do something restorative and balancing, like swimming mid-morning, but this is impossible. Commuting also takes its toll.

The helpline work she does can be draining but it is also rewarding and can change people lives. However, when she feels vulnerable herself, it is hard to help people effectively so this might not be the best job for her. In the future she wants to do work that is empowering and to be in situations where she has a choice and knows she can walk away at anytime.

Working and studying together helped Emily keep things in perspective and reduce stress. However, having mental health problems has changed Emily's career plans and ambitions; she decided journalism would be too stressful, and needs something structured without a lot of overtime and with regular time off.

The University's support structures were not effective, they did not provide a personal tutor and Emily had to explain her illness and situation to all the staff individually. This was taxing and humiliating. Her grades had gone from a high average to regular fails, but these warning signs were not picked up.

Emily found the student counselling service useful and, although she hated seeing her psychiatrist, in retrospect she realises it was worthwhile. Psychotherapy has also helped. However, she felt humiliated and ignored by her GP.

Before she was ill, Emily was only involved in the student world, she didn't have any contact with other parts of the community in the city. Once she was ill this made it hard to access NHS or voluntary sector services. She felt quite excluded. Service providers seem to exist in different bubbles and if you aren't in the right bubble, you don't get services.

She didn't understand 'the system' when she was first ill. If someone had told her what was going to happen and provided information about what was available, like advocacy, she would have felt less frightened and lost.

What has been most helpful, though expensive, is to mix and match western medicines from the NHS, with complementary therapies. When trying to create a holistic plan she found no one wanted to talk about what other agencies or practitioners might offer. In work terms, Emily feels people need help to sort out the gaps in CV's and to put themselves across positively in interviews.

Emily feels her experiences have made her a better person. She has more respect for herself and values healthy relationships. She has a real drive to change society so that people who are ill have more choice and control.

Case study - Robert

Robert is in his 40's, married, with one child. He has a diagnosis of manic depression. He lost a senior job with a food manufacturing company over 5 years

ago. For a time the high profile stressful job had suited him - he was often slightly manic and able to work long hours and cope with pressure. When he got severely depressed for the first time and felt suicidal he took time out. His employer provided full pay for nine months as well as other benefits.

When he seemed able to go back to work he was offered a less responsible role with the same pay as before. This seemed very generous. The doctor had recommended that Robert should start working one day a week and gradually build up to 3 days a week over several months. However, Robert went back to his employers onto a full-time intensive training course. He could not cope with this and left his job. In retrospect, although the company seemed caring, they made it difficult (perhaps impossible) for him to return successfully.

At the time his wife was also made redundant. When they ran out of money, as Robert was not well, she went back to work and Robert took on the childcare for their 18 month-old daughter. He finds this role important, enjoyable and rewarding; he is now "proud to be a house husband". He doesn't miss his high status role, but he misses the social interaction at work. Two friends, who were colleagues, have avoided any contact with him since he left work; and Robert felt there may have been rumours about him going around the office. This avoidance left him feeling angry and hurt.

Robert's values have shifted since losing his job: as well as being a parent, his faith is now very important to him. He got involved in fundraising and other activities at his church. However, when depressed, he loses his faith and so he has chosen not to continue as assistant church warden. When thinking about possible work in the future he would like to be able to do something worthwhile, possibly in the mental health field, as opposed to something mainly focussed on money. This would help him stay well. He has two sisters also diagnosed with manic depression and, all told, there has been great deal of family disruption for the last 10 years. Recently, Robert has been able to help one of his sisters begin to address the effects of her illness, and this has helped him too.

Robert continues to be affected by his illness. He tends to hide his depression, stopping most activities except childcare, which he does with a struggle. He sees old friends when he is well, not when he is ill, and has lost some of his hobbies. His wife has been marvellous. His GP is excellent and his Community Psychiatric Nurse has been very helpful, as have the PACT team. He has found the Manic Depression Fellowship (MDF) useful and he is an active member of the local MDF self-help group.

He feels his journey has led him to become a better person, "my sense of who I am has definitely improved ... I was previously in a pretty high pressure but nevertheless superficial world of big business. I worked ridiculously long hours and gave little time or love to my family. I believe I'm now a more well rounded individual and I have tried to learn important messages from some of the horrific experiences I've had ... I acknowledge now that I was probably on the path to destruction ... childcare has helped immensely in many areas."

Case Study - Chloe

Chloe is 38, single and lives alone; she hears voices and suffers from depression. She first became ill at 19 as a student and left her course. Six years later she started a degree in the performing arts, graduating with a 2:1. Chloe has always loved dance; in 1995 she was seeking work as a self-employed dancer and dance teacher when she had another episode of illness and, as before, was hospitalised. She then spent some time on benefits while doing some dance teaching; later she had some support from a specialist employment service to try administrative work, initially on a voluntary basis. Chloe subsequently worked for two years in reasonably paid administrative jobs. However, she became ill again - organisational change led to stress at work and, she felt she was put in an impossible situation. She had also recently been through a difficult relationship. She resigned but later regretted it. Chloe was qualified as an Alexander Technique teacher, and decided to teach rather than get another administrative job. Although she earned reasonable money this was a difficult experience; Chloe became very depressed and made a suicide attempt. Soon after she took on a part-time administrative/ receptionist's job where she did not feel supported and often worked alone. Her voices came back and she took 2½ days off sick. At the end of her probationary period, while unwell but still at work, her job was terminated without warning. No one had previously found her work inadequate so she felt the dismissal was related to her illness, though nothing was said. Eight months later she successfully took her employer to an Industrial Tribunal for discrimination and received some financial compensation.

Chloe has felt stigmatised more than once. When she resigned from her job she felt that the organisation should not have accepted her resignation so quickly; they could have found out more about her situation and illness. She feels she did not make a good decision herself because she was in a crisis and this was exploited.

Chloe's working history is painful; she feels she was not able to 'make it' doing the things she really wanted to, like teaching dancing and Alexander Technique. Dancing was a dream and she still feels bereaved about this loss. Now it is difficult to trust her own judgement - perhaps it is not realistic for her to do these things? She found being self-employed isolating and depressing. She struggled with very high expectations of herself and without feedback she had no sense that she was doing well. Chloe has been rather dismayed to discover she needs the structure and back up that an organisation provides; she also realises she needs to be with other people.

Chloe is well qualified and has a lot of skills, yet she finds it difficult to envisage her future. She feels stuck. Although in some ways her health is better than it has been for some time, she is unsure about trying paid work again, wondering whether she has sufficient strength and enthusiasm, and fearing she will not be able to cope again. In some ways, Chloe just wants to stay at home and feel calm and not have anything too difficult to

deal with. She has enjoyed not having many responsibilities and is involved in a lot of different activities. She is doing a Further Adult Education Teaching Certificate, taking classes in art and French, teaching some Alexander Technique, volunteering in a charity shop and is secretary of a mental health survivor group. Chloe would also like to do more campaigning work in the mental health field. Although these things feel worthwhile, earning a living is very bound up with being a 'proper adult' and with her self-image and identity. When she was earning a reasonable salary Chloe felt great, not being on benefit was a real marker of being 'normal', and of independence. She is caught between feeling she should get a job so she can feel better about herself and not wanting to go through all the problems again.

Chloe wants to be seen like anyone else - because she hears voices it doesn't mean she is always in crisis or need special treatment - and therefore often does not want to disclose her mental health problems to employers. When she is ill she just wants an employer to understand and be supportive; there is not much more they can do.

Chloe feels her own negative thinking can be a problem, as was her initial determination to sort things out on her own. Chloe does not like the psychiatric system; she has had bad experiences with doctors and feels hospital doesn't help her. Chloe feels that treatment is too medication led, and therefore very limiting. One drug she was on for four years stopped her dancing, making her feel heavy and stiff; she was also depressed and this made her feel worse. In the last year the Crisis Team has helped Chloe to stay out of hospital, but she saw six different people in three days, so the service lacked continuity.

Chloe feels there should be much more emphasis on social and psychological issues and she sought Cognitive Behavioural Therapy (CBT). She waited 18 months and then had her appointments cancelled without notice when the psychologist was ill. The therapist was not replaced. This unprofessional approach put her off seeking therapy from the NHS. Private psychotherapy has been more helpful.

Isolation is a problem for Chloe - she is housed by a Housing Association and lives alone. She does not think this is good for her as she tends to withdraw, she would like help to consider other options.

Chloe has found reading and the hearing voices movement helpful. One book really changed her point of view³ and she now feels being active and being with people are really important.

If the benefits system were more flexible, Chloe would like to do more paid work and to try different things out, like working in a bookshop on a paid basis. However as things stand, Chloe feels she has to be willing to do something for a long time and be able to make a serious commitment. Chloe is quite concerned that 'recovery' programmes, although

¹ Professor Marius Romme and Sandra Escher (1993) *Accepting Voices*, Mind Publication

positive in some ways, should not put pressure on people to get back to a 'normal' life, i.e. full-time work, when they aren't ready. She feels that different contributions to society should be valued, not just paid work. In her ideal world people would get a proper wage whether working or not.

Discussion

Our study describes the major significance of loss of occupation for people with mental health problems. The impact of loss of occupation, as well as the accompanying distress, is likely to be missed by health and social care services because they do not focus on these issues. Most people had no help from professionals with the transition back into an occupation. People have not 'just' lost their jobs: their history, skills, confidence, and experience also tend to disappear, at least temporarily. Identity and purpose in life are also affected. Given these multiple hardships, we feel that services should focus more on the broader impact that mental health problems have on people's lives and work directly with people's experiences of loss.

Stigma and Discrimination

We asked why people had lost their occupation. Many people felt too stigmatised to return to work, or 'voluntarily' removed themselves. 16% of people refer to embarrassment after being unwell as the main reason for losing occupation. This figure exceeds the findings in an earlier study by the Mental Health Foundation (2002, p. 28), that gave a figure of 12%. One possibility might be that workplaces find it easier and more 'convenient' if the person with mental health problems removes themselves from the situation. We have found little evidence of employers making serious attempts to enable people to stay in their jobs. Perhaps this is not surprising given that everyone in our sample lost their occupation through mental health problems. However, our participants have also reported active discrimination and harassment at work. Many employers do not understand or support people with mental health problems, and the workplace can often be a source of stigma and discrimination.

A report on attitudes to mental health in the workplace by Blackwell, Burns and Hardy (2001, p. 3) concludes that mental health discrimination - either direct or indirect - is likely to be common. They found that discrimination is not limited to personnel and employment matters such as recruitment and promotion, it extends into actively hostile behaviour towards those with mental health problems. It was exacerbated by manager indifference or ignorance of the issue. Understanding and awareness of mental health issues was disturbingly low among employers, managers and employees, and there was a serious absence of expert information, advice or help. Employers clearly need to do more to combat stigma and discrimination.

Work-Life Balance

Although a majority of people in our study found their previous work rewarding, many had work that did not satisfy them and/or reported stresses that had contributed to mental

health problems. Some had endured difficult situations at work in jobs that made them sick. The Mental Health Foundation's *Out at Work* survey (2002, p. 26) found that two-thirds of people believed that unrealistic workloads or pressures at work had caused or exacerbated their mental health problems - nearly as many believed that bad management was one of the key issues. Kate Stanley, writing in *The Guardian* (7/7/03) notes that more and more people are defining themselves as disabled, and the most commonly cited reason given for being unable to work are mental health problems, often linked with workplace stress.

In our society work is a key part of identity, and is associated with money, independence and status. The 'norm' is assumed to be full-time paid work and many people spend the majority of their lives working. However, these social values contribute to a poor work-life balance and mental ill health.

The Mental Health Foundation's report, *Whose Life is it Anyway?* (2003) describes the effects of a poor work-life balance. It states that one in three workers will have a mental health problem in any one year and half of all working days lost are due to work-related stress. One in six people are working more than 60 hours a week and UK workers average the longest hours per week in Europe (ibid). The longer-term implications of a demanding work culture can increase the risk of mental health problems. The report shows that many people are neglecting the factors in their lives that make them resistant or resilient to mental health problems: exercise, quality time with partner and/or friends, social activities, hobbies and entertainment.

Our study indicates that traumatic experiences have led many people to change their values and adopt a significantly different work-life balance. Such changes are frequently described as positive. However, these choices tend to be accompanied by a marginalised existence: lower status, less money, and awkwardness about role. We are left with the question: can we be valued without paid occupation? In our society adopting values that are better for mental health seems to be at odds with the norms of working life - very few of our participants now have full-time paid work. Being excluded from mainstream employment is an obvious problem for people with mental health difficulties, but working norms that tend to undermine mental health for many in full-time work is an even bigger social issue. Does our society foster an over-emphasis on work?

Many of our participants have felt their lives lack a sense of purpose and meaning, and experienced times when they felt excluded and disengaged from society. This emptiness is likely to reinforce and sustain mental health problems, to create depression and despair, and to emphasise rather than moderate suffering. Occupation and activity can be experienced as a means of becoming and staying well. They provide social contact, and structure, as well as a means of contributing to society and making life more meaningful. These points are reinforced by another *Strategies for Living* study into mental health and employment (Harris, 2003) where all participants believed work was important for mental health, providing the type of work, conditions and mental health considerations were taken

into account. Work in this study was seen as leading to a vital involvement in the world and *"a desirable alternative to sitting at home 'staring at four walls' and brooding about their difficulties"* (ibid, p. 11). Again work was seen as providing opportunities for social interaction. Being able to participate in occupation is likely to play a vital part in regaining mental health: enabling people to rediscover their skills; rebuild their confidence; and re-establish a more fulfilling life. This creates a virtuous cycle that supports good mental health. Occupation, broadly defined, should therefore be as widely accessible as possible, be seen as therapeutic and as a key part of what is needed to rebuild life.

Identity

Our research vividly describes the deeply painful consequences of people losing their occupation following mental health problems. Not only is being ill distressing and life changing in itself, but other aspects of life are utterly disrupted, including identity. People are often socially excluded and poverty excludes them further, Davis & Hill (2001). People describe themselves as feeling a failure and ashamed. Having these problems is often experienced as a guilty secret. Ordinary social questions like 'what do you do?' become a minefield triggering strong negative feelings.

Participating in society with such experiences exposes us to awkward questions that are both hard to answer and hard to avoid. We are faced with potential stigma and discrimination if we are honest, and to feeling vulnerable and fraudulent if we lie. Choosing to protect ourselves by not participating in society creates further isolation and marginalisation. These are impossible choices. Webster (2002) points out that job applicants are put in an invidious position. *"They face the choice between disclosing a mental health problem and the fear of subsequent rejection, or of concealing their medical history and putting themselves 'at risk' of dismissal for gross misconduct should their illness later come to light - due to a relapse for example."*

Such experiences are linked to the idea of 'spoiled identity' as described by Goffman (1963). He details situations where something disqualifies a person from full social acceptance, the person is then potentially 'discreditable', and is called on to 'manage' their identity, for example, to decide when and where to reveal vulnerability to mental illness, and how to present it or conceal it at any moment. He describes a process of 'passing' for normal with an ever-present fear of exposure. *"By intention or in effect the ex-mental patient conceals information about his real social identity, receiving and accepting treatment based on false assumptions concerning himself."* (1963, p. 57).

Valuing Skills

As well as identifying stigma and discrimination at work, we have seen that some health professionals actively damage expectations by assuming that people will not be able to

work, or will only work in a menial or low paid capacity. A number of other services also seem to embody similarly low expectations and assumptions of low pay: for example return to work guidance and the benefits system. The Permitted Work rules⁴ allow for 16 hours work assuming minimum wage levels. Attitudes and regulations like this can reinforce stigma and discrimination from other sources.

People value occupation highly and want to find suitable opportunities; indeed many in our sample have been very persistent and resilient in seeking occupation in the face of repeated losses. Most of our respondents are experienced, highly skilled and very much want to contribute to society. Our findings are supported by a report from the Royal College of Psychiatrists (2003). They find that a large proportion of people with psychiatric disabilities want jobs and also assert that they *"have the potential to get and keep them provided that there are available schemes and opportunities and that reasonable adjustments are made in the workplace."* The Strategies for Living Report Summary (Mental Health Foundation, 2000, p. 5) also describes people as finding purpose in their lives *"through employment or through other meaningful daytime activities"* and that having something to get up for on a day-to-day basis is sustaining.

Getting Back to Occupation

Despite skills and the wish to do more, many are unable to find an occupation, and struggle to find a sense of purpose and a way of being involved in society. Our respondents perceive significant barriers to regaining an occupation: having to disclose mental health history, lack of confidence, fear of getting ill, fear that they couldn't get work (or only low paid work), and loss of benefits. Harris (2003, pp. 23-27) has identified similar concerns about disclosing mental health history linked to fears of discrimination, fear of getting ill again and fear about loss of benefits (2003 p. 15).

Barriers to occupation are clearly reflected in the high unemployment rates for people with mental health problems. For people with the diagnosis of a Severe Mental Illness unemployment rates rise as high as 60-100%, (Royal College of Psychiatrists, 2003). They see this high rate of unemployment as being as much a product of social factors, as of the personal consequences of mental illness. Barriers to work for people with Severe Mental Illness are described as including structural factors, stigma and prejudice, attitudes and approaches of the mental health services, and the lack of well-run employment schemes (ibid, 2003).

¹ Further information on benefits, service user involvement and payments can be found in The Mental Health Foundation's briefing paper *"A fair days pay"* by Judy Scott (2003) which provides advice to potential employers and to service users who are considering becoming involved in improving services.

Lack of flexibility in the benefits system is another problem that is confirmed in other studies - one respondent said "(If you) *say you're well you lose benefits, but you don't know if you will cope with something until you have tried, so how do you know?*" Harris (2003, p. 28). This study identified people's fear of giving up their benefits and then finding themselves unable to work; participants also described the system's 'black and white' definitions of ability to work as unhelpful. One person described in this study was told "*if you can work voluntarily you can go out and get a full-time paid job*", Harris (2003, p. 29).

Changes to the benefits system are recommended in research done by the Health Action Zone Fellowship Programme, Witton (2001). They found that benefit issues continue to be one of the major barriers to work. Users reported the need for informed reassurance from employment support workers and access to expert advice at each stage of the transition in and out of work. They recommend government policy changes to create 'Welfare to work' policies that recognise, address and communicate the importance of an adequate and secure income when out of work as necessary for improving mental health and thereby enabling people to return to work. They also recommend that "*the benefits system must be more flexible to reflect the fluctuating and unpredictable nature of mental ill health by encouraging and rewarding the contribution of voluntary work, part-time work, training and other work activities. These activities have positive health outcomes in themselves as well as providing stepping-stones to full-time paid employment.*"

While barriers to work need to be dissolved, it is also important that people should not be forced into employment. Threats are disabling and likely to result in risk-averse behaviour. We feel it is much more appropriate for employment services and the Department of Work and Pensions to take an encouraging and supportive approach to people who have experienced serious trauma and distress. "(People) *should have the opportunity for progression towards paid employment, but they should not be forced to move on to situations of greater stress and responsibility if they do not wish to*" (Royal College of Psychiatrists 2003).

The Need for Specialist Services for All

Effective support services are either not available or in short supply. In Bristol there is a Work Development Programme that is a NHS Beacon award winner. One of the findings in their research was that people's jobs after the onset of mental health problems lasted only an average of nine months. A job maintenance group was established to tackle this issue. Within this programme 'work' is seen as a spectrum of activity ranging from hobbies and courses, through training, volunteering and work placements to eventual full or part-time paid employment. Within the group clients are at any of these 'levels' and provide mutual support and encouragement. The group seeks to slow down the process of getting back to 'work' and insert missing rungs into the ladder, so people can gradually develop their confidence (Butterworth and Dean, 2000). Within this Work Development Programme there are Work Development and Vocational Advice Teams which have developed a policy on job retention. The Team's role is described as ensuring that occupational health, GP's, mental health teams, personnel managers and employers are all kept in the picture - something that is acknowledged as impossible for the service user when they are ill. They have been successful in supporting people to retain their jobs, and it is clear that it would be helpful if more people managed to do this. More services like this should be available. Although these are local services that have received national recognition, the majority of our participants from Bristol have not had access to them, and most of our participants didn't know they existed. Good quality specialist support should be available for all, not just a lucky few.

Flexible Workplaces

As well as specialist services to help people engage in meaningful activity and occupation, the workplace needs to change. The working environment should accommodate people's mental health needs and vulnerabilities as well as physical disabilities. The need for flexibility is strongly emphasised in our study. People want flexible working hours and practices. They fear getting ill and quite rightly do not want to put themselves in risky situations. People should be able to manage stress levels and look after themselves appropriately **and** be able to do paid work. The Royal College of Psychiatrists supports the need for flexibility when they suggest that ideally people should have access to a range of work, training and support which is relevant to their changing needs (2003). Harris (2003, p. 21) also identifies the need for flexibility and reports that the majority of participants felt that changes to work environments would vastly improve their chances of being able to maintain employment.

People with mental health problems are not the only ones who want flexibility at work. In a government-backed survey reported by *The Guardian* (2/1/03) job hunters put flexible working hours above other benefits such as a company car or even a higher salary. Almost half of men and women surveyed chose flexible working as the benefit they would most

value in their next job and more than two thirds said they would like the chance to work more flexibly when necessary. The research, however, highlighted a continuing gap between the flexibility employees want and the packages offered by many employers. *"This research is a real wake up call for employers ... Too many organisations seem to be missing out on one of the most effective ways to attract top talent."* It seems that not only would more flexible working practices benefit people with mental health problems, they would act as a magnet for attracting and retaining all staff.

A New Framework

Writing about the number of disabled people⁵ who are keen to return to work, Kate Stanley (The Guardian, 7/7/03) argues that a new public policy framework is required to transform the expectations of individuals, employers, the government and non-governmental organisations in the way disabled people are supported to stay in or enter work. Individuals *"should expect to be supported at work and receive proactive rehabilitation interventions. Employers should expect to deliver policies such as flexible working patterns and make necessary reasonable adjustments to accommodate the needs of disabled employees (as they are required to do by law)"*. She also suggests that the Government should expect Jobcentre Plus "to focus on ensuring it can deliver effective welfare-to-work options for disabled people, rather than imposing more conditions on benefits receipt which people may struggle to meet".

It seems that the 'system' - health and care professionals, government and benefits agencies, employers etc - tend to see us as either well, and therefore able to do paid work 'like anybody else' or ill, and unable to do anything. However, the more complex reality for many of us is that we have ongoing vulnerabilities. Our study supports this view. We may be able to stay well for long periods and make a significant contribution to society, and this may depend, for example, on having ongoing support in place, on not working full time or having too much stress. We may, on the other hand, have periods when we are unstable and need much more support. We need a 'system' which recognises shades of grey and responds accordingly. This kind of approach seems to be reflected by Grove's idea that a comprehensive mental health employment service should contain a *"spectrum of opportunities"*, with possibilities to access this spectrum at any point and to move, or stay, according to individual needs (1999).

Final Comments

Our participants' stories do not describe a smooth progression from a place of 'illness' to a place of 'well being', far from it. Instead they describe a difficult journey with many ups

¹ More than a third of people reporting long-term health problems have mental or behavioural impairments i.e. have some kind of mental health problem.

and downs along the way, so an occupation that might be appropriate at one stage, might not be at another. Nor do we have any evidence that this journey ends. We have seen that people are seeking support in a whole range of areas to help them sustain their ability to continue the journey in hope, without giving in to despair, and to help them find the strength to struggle with the difficulties along the way.

It has been very encouraging to see that many people in our study feel that their sense of self is changed for the better despite, and because of, their experiences. People have reported positive changes in their values and priorities: they have become clearer about who they are and what is important in their lives; they have developed more understanding of others; they have carved out better-balanced and healthier lives - they have made these changes by drawing on their own resources, inner strengths and resilience. This is a message of hope. Lives can be rebuilt, identities can be reconstructed and strengthened despite loss and suffering. Such outcomes might be more common in society if people with mental health problems were included and supported more effectively. This would mean more people could contribute at less personal and social cost. We hope our work will help to generate such change.

Recommendations

We recommend that mental health and social care services:

- Become more holistic and concentrate more on occupation.
- Acknowledge and address people's experiences of loss associated with occupation.
- Provide more flexible and ongoing support to help people reconstruct their lives.
- Always include plans for meaningful activity and occupation within the Integrated Care Plan Approach (ICPA).
- Ensure that everyone working with people with mental health problems is trained to combat stigma and discrimination.
- Provide open access to a specialist support service for everyone who wants to increase their activities and/or engage in occupation, independent from the benefits system. This service to offer a wide range of options and comprehensive and up to date information.
- Recognise that occupation is both therapeutic and vital for social inclusion and, therefore, work with a wide range of statutory, voluntary and commercial organisations to increase access to occupation including opportunities to volunteer and study.
- Respond to the person behind the mental health problem, respecting their intelligence, skills and past experiences as strengths to build on.
- Become person-centred and tailored to individual needs at a particular time i.e. are not delivered on the basis that 'one type fits all'.
- Make a radical shift away from a focus on illness and crisis management to a focus on health and rebuilding lives.

We recommend that employers:

- Provide a working environment that sustains good mental health for everybody.
- Recognise the Duty of Care for their employees' mental health as part of their Health and Safety policy and practice.
- Develop systems to identify and support employees at risk of suffering from stress.
- Take serious action over all harassment and bullying at work.
- Provide a flexible working environment for people with mental health problems, both in relation to hours worked and working practices.
- Adapt the working environment to accommodate people's unique mental health needs and vulnerabilities.
- Combat stigma and discrimination around mental health problems in the work place as rigorously as sexism and racism.
- Include the needs of people with mental health problems in Equal Opportunities policies and practices.
- Provide active support to help people with mental health problems retain their jobs.

We recommend that the Department of Work and Pensions:

- Creates a benefits system that recognises the ups and downs of mental ill health and accommodates them flexibly without imposing penalties.
- Develop a benefits system that enables people with mental health problems to engage in occupation rather than one that generates obstructions.
- Makes sure that training and employment services for people with mental health problems recognise that people have intelligence, skill and experience to build on, and do not make assumptions that people can only do menial work on low pay.
- Ensures that everyone working with people with mental health problems is trained to combat stigma and discrimination.

We recommend that education and training institutions:

- Develop early warning systems to identify and support students and trainees at risk of suffering from stress and/or mental health problems.
- Offer appropriate information and support to students and trainees.
- Undertake mental health awareness training and establish better links with mental health services.

We recommend that organisations offering opportunities to volunteer (for example volunteer bureaux):

- Recognise, and are supported to develop, their role in enabling people with mental health problems to take up voluntary work.
- Undertake mental health awareness training and establish better links with mental health services.

We also recommend that:

- Mental health awareness training is provided much more widely in all organisations and services.
- Effective partnerships are established between all organisations involved in health, social care, education and training, employment, leisure and arts, volunteering, social activities and housing, to enable people with mental health problems to be more included in meaningful activity and occupation.
- The Disability Discrimination Act is implemented to protect people with mental health problems as effectively as those with physical disabilities.

References

- Blackwell, T., Burns, P., & Hardy, S. (2001) *Working Minds. Attitudes on mental health in the workplace, with proposals for change*. For the **Mind out for mental health** campaign. The Industrial Society, London.
- Butterworth, R., & Dean, J., (2000) 'Putting the Missing Rungs into the Vocational 'Ladder"', *A life in the day*. 4 (1) February 2000: 5-9.
- Davis, A., & Hill, P. (2001) *Poverty, Social Exclusion and Mental Health in the UK 1978-2000. A Resource Pack*. Mental Health Foundation publication for Focus Project 2000, London
- Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Penguin, London.
- Grove, B. (1999) 'Mental Health and Employment. Shaping a New Agenda', *Journal of Mental Health*. 8, 131-140.
- Harris, J. (2003) *Employment and mental health problems*. Mental Health Foundation, London.
- Mental Health Foundation (2000) *Strategies for living. A summary report of user-led research into people's strategies for living with mental distress*. Mental Health Foundation, London.
- Mental Health Foundation (2002) *Out at work. A survey of the experiences of people with mental health problems within the workplace*. The Mental Health Foundation, London.
- Mental Health Foundation (2003) *Whose Life is it Anyway? Summary of the Mental Health Foundation's report on the effects of a poor work-life balance on mental health*. The Mental Health Foundation, London.
- Royal College of Psychiatrists (2003) *Employment for all: assisting people with mental health problems and disabilities into work. A response to the House of Commons Work and Pensions Inquiry*. www.rcpsy.ac.uk
- Stanley, K. (7/7/03) 'The missing million. With a third of unemployed disabled people keen to return to work the government needs to find a long-term strategy for reintegration', *The Guardian*, London
- Ward, L. (2/1/03) 'Workers put a premium on flexible hours', *The Guardian*, London
- Webster, A. (2002) 'Grasping the nettle with employers: defining the problem, identifying solutions', *A life in the day*. 6 (2) May 2002: 26-31.

Witton, D. (2001) *Communicating Welfare Benefits: Developing an integrated approach to resolving the benefit barriers to work experienced by people with mental health problems. HAZ Fellowship Research Summary.*

Further Reading

Allott, P., & Loganathan, L., (2002) *Discovering Hope for Recovery from a British Perspective. A review of a sample of recovery literature, implications for practice and systems change.* Centre for Community Mental Health, University of Central England in Birmingham.

Bates, P. (2003) 'A pathway to employment', *A life in the day.* 7 (1) February 2003, 4-5

Batty, D. (13/2/2001) 'Stigma of mental illness damages job prospects and earning power', *The Guardian*, London.

Clark, S. (2003) 'Voluntary work benefits mental health', *A life in the day.* 7 (1) February 2003, 10-14

James, K. (2003) 'Learning and the link to positive mental health', *A life in the day.* 7 (1) February 2003, 15-20

Mee Ling Ng, Pozner, A., Hammond, J., Palfrey, C. & Rudd, L. (2001) *Working Futures. Executive Summary. Valued Occupation for People with Mental Health Problems in Powys. A Development Strategy.* Powys Agency for Mental Health, Wales.

Queensland Nurses' Union (8/11/1999) *Countries working less hours record faster productivity gains.* www.qnu.org.au/ilostudy.htm

Workstress.net (2003) *UK National Work-Stress Network News. UK and European Hazards Campaign - January 2003.* www.workstress.net/newsletters/newsjan03.htm

Appendix 1 : Questionnaire: including all questions asked and statistical results

Note : Based on a total sample of 56 people. Results are expressed in percentages. The sample for each question is listed on the right.
There are no statistics for the qualitative responses.

Question							Sample
1. Are you	Male?	Female?					
	36	64					56
2. Are you	Under 25?	25-34?	35-44?	45-54?	55-64?	65+?	
	5	14	41	23	14	2	56
3. Please describe your ethnic group							
4. Do you have dependent children, or other people, to care for:	Yes?		No?				
	27		73				56
5. What occupation(s) did you leave due to mental health problems?							
6. How long ago did you leave your occupation? (in months)	Up to 12		13-36	37-60	60+		
	11		30	13	45		53

7. Did you find the occupation you left ... ? On a scale from 1 to 5

	1	2	3	4	5		
Unpleasant	9	15	29	35	13	Enjoyable	55
Boring	6	7	11	43	33	Stimulating	54
Bad for your confidence	18	16	26	24	16	Good for your confidence	55
Difficult to fit in with	13	26	29	16	16	Suited you	55
Took too much time	22	30	9	32	7	Useful for occupying time	54
Damaged your status	15	4	21	38	23	Improved your status	53
Limited your social life	22	17	43	15	4	Improved your social life	54
Damaged your sense of who you are	21	23	4	38	15	Contributed to your sense of who you are	53
Meaningless	13	9	11	39	28	Meaningful	54

8 When you left your occupation, how did you leave? (Please circle any that apply.)

	Yes	
Asked to leave	11	6
Left voluntarily	23	13
Encouraged to resign	11	6
Felt too embarrassed to return after being unwell	16	9
Other reasons (please describe)	54	30

9. How did losing your occupation affect your ... ? Including space for comments.

	Negatively			Neutral	Positively			
	-3	-2	-1	0	1	2	3	
Confidence	48	33	6	8	2	4	0	52
Self-esteem	48	33	7	7	2	2	0	54
Use of time	30	30	15	9	7	7	2	54
Friendships	24	15	30	22	0	6	4	54
Sense of Purpose	43	30	11	11	2	2	2	54
Future plans and ambitions	48	19	9	13	7	2	2	54
Independence	42	19	19	11	6	2	2	54

10. Do you think that other people see you differently since you lost your occupation?

If you circle yes, please describe what has changed for you.

	N/A	Yes	No	Don't Know	
Your partner	63	24	11	2	54
Your child/ren	72	19	7	2	54
Other family members	11	64	16	9	55
Your friends	4	51	29	16	55
Your neighbours	26	30	26	19	54

Others - Who?

11. Have you ever avoided people, places or situations which are connected with the occupation you used to have?

If possible please add a comment.

No	27	
Occasionally	16	
Several times	20	
Often	36	55

12. Since you lost your main occupation, have you done any work/study which you have not been able to continue?

Yes	No	
57	43	54

If YES, how many times did that happen?

1	2	3	4	5	6	
37	37	19	4	0	4	27

Please comment on how any attempt(s) have affected you (e.g. your confidence, mental health, self-esteem, etc)

13. What do you see as issues about taking up voluntary or paid work or study again?

	very important	quite important	not important	
Decided not to work/study	38	21	41	42
Concern about losing benefits	60	25	15	53
Lack of confidence	67	31	2	52
Fear of getting ill again	68	28	4	53
Fear you could not get work	56	39	6	52
Fear you could not study again	38	40	22	50

13. (Continued) What do you see as issues about taking up voluntary or paid work or study again?

	very important	quite important	not important	
Having to take a low paid job	40	42	18	50
Disclosing mental health history	60	34	6	53
Not sure about what to do	47	36	18	45
Other (please write in)				

14. What kind of help or support do you think could be, or was, useful for returning to work / study?

1 = no use at all, 2 = some use, 3 = quite useful, 4 = very useful

	1	2	3	4	
Work "taster" schemes	14	18	37	31	49
Specialist "return to work" guidance	10	12	31	47	51
General careers guidance	14	22	26	39	51
Occupational therapy	31	15	33	21	52
Confidence / assertiveness training	8	21	34	38	53

14. (Cont.) What kind of help or support do you think could be, or was, useful for returning to work/study?

1 = no use at all, 2 = some use, 3 = quite useful, 4 = very useful

	1	2	3	4	
More flexible benefits system	7	9	17	67	54
Help with applications / job search	9	17	38	36	53
Flexible working hours	0	13	28	59	54
Voluntary work to start with	9	16	20	55	56
Part time work to start with	4	16	22	58	55
Flexible working arrangements	2	11	20	67	54
Ongoing support from Key Worker	13	13	22	53	55
Support arranged at workplace/college	7	24	28	41	54
Other useful support, please describe.					

Section B - For people NOT doing regular voluntary or paid work or study at present.

Completion of section	Yes	No	
	48	52	56

15. Do you regularly involve yourself in any activities?

	Yes	No	
	75	25	28

16. Look at the following activities and circle the codes to show

Whether or not you do this (Yes/No)
 How often you usually do this? (D = Daily, W = Weekly, M = Monthly, O = Occasionally).
 How satisfying you find it? (V = Very Satisfying, Q = Quite Satisfying, N = Not Satisfying)

	Do this?		How often?			How satisfying?			Yes/No *
	Yes *	D	W	M	O	V	Q	N	
Care of children / others	58	47	27	7	20	60	40	0	26
Training or courses	50	0	46	15	39	50	36	14	26
Physical activities	85	36	50	14	0	46	46	9	26
Hobby or interest	57	38	44	6	13	73	27	0	28
Attending day hospital	15	33	33	33	0	33	67	0	26

16. (Continued) Look at the following activities and circle the codes to show

Whether or not you do this (Yes/No)
 How often you usually do this? (D = Daily, W = Weekly, M = Monthly, O = Occasionally).
 How satisfying you find it? (V = Very Satisfying, Q = Quite Satisfying, N = Not Satisfying)

	Do this?		How often?				How satisfying?			Yes/No *
	Yes *	D	W	M	O	V	Q	N		
Medical appointments	89	0	13	61	26	10	43	48	26	
Attending support groups	63	0	59	29	12	41	53	6	27	
Social activities	74	10	45	20	25	42	47	11	27	

If you do other types of activity please write them in below.

17. Do you feel the activities you currently do have affected the following?

	Improved	No effect	Made worse	
Your confidence	82	15	4	27
Your sense of purpose	63	33	4	27
Your contact with others	85	11	4	27
Your self-esteem	67	26	7	27
Your mental health	74	26	0	27

If you would like to comment on particular activities, please do so here.

18. Would you like more support to help you get involved in more activities or an occupation?

Yes	Might be helpful	Not really	No	
39	39	21	0	28

19. Would you like to do more voluntary or paid work or study?

Yes	No	
79	21	28

Section C - For people now working (voluntary or paid) or studying, however few hours.

Completion of section	Yes	No	
	68	32	56

20. Are you doing (please circle more than one if they apply).....

	Yes	No	
Paid Work?	82	18	22
Voluntary Work?	92	8	25
Study?	70	30	20

21. How many hours in total do you work per week (include both voluntary and paid work)?

	1-7	8-15	16-22	23-29	30+	
	32	18	26	11	13	38

22. Did you receive help or support to take up your current work or study from any of the following?

Note that numbers answering Yes/No are significantly higher than second part of the question

	Did you receive help?		How helpful were they?					Yes/No *
	Yes*	No *	Not helpful	1	2	3	4	
Your previous employer/s	14	87	78	0	0	22	0	37
Health or Care Professionals	43	57	24	6	0	41	29	37
Family and / or Friends	54	46	14	14	10	29	33	35
Government/Benefits Agencies	31	69	50	0	21	7	21	36
Occupational Health/Student Services	14	86	56	11	0	0	33	35
Employment Agency or Volunteer Bureau	27	74	25	8	33	17	17	34
Support Group/s	42	58	25	6	13	25	31	33

Please write in which health professionals, which groups and any other sources of help.

23. Please tell us what most helped you return to occupation?

24. If you compare your current work / study with the work you had before your mental health problems:

Do you now take more or less responsibility?

Do you work more or less hours?

A lot more 13

8

More 11

8

About the same 13

11

Less 21

27

A lot less 42

38

46

37

25. Are you paid?

Is your total pay more or less than before?

Not paid at all

A lot more

More

About the same

Less

A lot less

42

3

3

11

8

34

38

26. If paid, is your rate of pay (hourly, monthly), more or less than before?

A lot more

More

About the same

Less

A lot less

5

10

10

20

55

20

27. Compared with your previous work, is your current voluntary or paid work or study.....?

	[Less]				[More]	
	1	2	3	4	5	
More or less satisfying?	6	16	24	29	26	38
Better or worse for your self-esteem?	5	13	32	29	21	38
More or less enjoyable?	5	16	16	32	30	37
Better or worse for your confidence?	5	8	32	29	26	38
More or less stressful?	38	35	11	5	11	37
More or less meaningful?	3	18	24	29	26	38
Better or worse for your mental health?	5	8	11	47	29	38

Section D: This final section is for everyone to complete

28. Below are listed some aspects of having mental health problems.

Please mark each one to show how much it has affected you., or N/A if not applicable

1 = not at all damaging through to 5 = very damaging

	N/A	1	2	3	4	5	
Being diagnosed / hospitalised / sectioned	2	11	11	13	20	42	55
Side-effects of medication	4	11	14	18	29	21	56
Prejudice and stigma around mental illness	0	0	13	25	23	39	56
Losing your work	1	9	5	13	21	50	56
Damage to relationships	0	5	11	25	29	30	56
Changes in future plans / expectations	0	11	7	11	15	56	55
Other, please describe.							

29. Do you think you have learned anything useful, as a result of the changes in your occupation?

Yes	No	Not sure
57	13	30

54

30. Have you changed your approach to any of the following as a result of the changes to your occupation?

Please give brief details if any apply.

Any change reported

Importance of work or study

77

56

The importance of leisure

64

56

The importance of money

77

56

Importance of social relationships

73

56

Having a purpose in your life

71

56

31. Has losing your occupation changed your sense of who you are?

If losing your occupation has changed your sense of who you are, in what way?

No

14

Yes, for the better

44

Yes, for the worse

31

Yes, in some other way

12

52

32. If a stranger asked you "What do you do?" what would you say?
33. How would you feel about being asked "What do you do?"
34. What do you think are three priorities for helping people to find a meaningful occupation following mental health problems?
35. Please use the space below, and overleaf, to add any comments or reflections on this questionnaire.

We would also be very interested to read an account, in your own words, of how the loss of your work or study has affected you, your confidence, and your sense of who you are. Please write whatever you can and continue on the next page if possible.