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**Evaluation of a Citizens Advice Bureau (CAB)
Mental Health Welfare Rights Project**

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Abstract

This report presents the findings from the first year of a welfare rights project in an in-patient hospital unit. The study, carried out by a group of service users and carers, found that a considerable amount of time was spent by nursing staff on welfare benefits prior to the introduction of a specialist welfare rights worker. The welfare rights project freed up staff time, reduced patient anxiety about benefits and related problems, and helped patients obtain extra benefit entitlement. Someone with knowledge and dedicated time can be beneficial for patients, their families and carers, and nursing staff and provides a point of contact with the various agencies. However, it became clear that welfare benefit problems can take time to resolve and the projects existence in in-patient units did not fully meet the needs of patients returning to the community or those being treated in the community.

Key words: welfare benefits; effectiveness of welfare rights work in in-patient units; service user and carer involvement in research.

Introduction

Mental illness is a significant issue in today's society with 16% of working age adults having a mental illness and, approximately half of those having a serious illness (ONS 2001). Mental illness also impacts on the economy in terms of the costs of treating people within the NHS and also in the payment of welfare benefits. Welfare benefits are a means of the State providing practical help and financial support for those who are unemployed and looking for work, or earning a low income. It may also provide support for those bringing up children, the retired, those who are caring for someone, or are ill or have a disability. According to Layard (2005) almost 40% of those who claim incapacity benefit (one of the benefits that may be paid to people under State Pension age who can't work because of illness or disability) have a mental illness. He also refers to the fact that people with mental health problems have the lowest rate of employment of any disabled group. However, mental illness can be a long term condition for many sufferers and this can impact on their ability to return to work after illness and to sustain their employment without adequate support. Allied to this is the fear of losing employment or entitlement to benefits through returning to work and becoming ill again following their return. This can only add to the stress of an already traumatic experience.

Although many people with mental health problems would like to return to work, preferably through a gradual return, the complexities of the welfare benefits system and discriminatory practices of employers act as a disincentive. For many the fear of losing or disrupting their income is a factor in their reluctance to seek work (Sainsbury Centre 2004). Working

more than four hours per week can lead to loss of Income Support (a benefit paid to those who are aged from 16 years to 60 that are on a low income) and other benefits such as Housing Benefit. Others fear that returning to work will mean a period without income when benefits cease and wages are paid in arrears and a loss of other benefits. Although there is assistance available for this transitional period it is not widely known and can make it a stressful period. If a person leaves work due to ill health they may be reluctant to go through the whole process of claiming for their previous benefit entitlement and thereby lose out on income.

Many of those people with serious or acute illnesses will have to spend periods of time in hospital as an inpatient. This can lead to periods of sick leave for those in employment or, if the episode of illness is long term, may result in unemployment through loss of work or inability to work. For those in receipt of welfare benefits, as a result of being unemployed or unable to work through illness or disability, going into hospital can lead to problems with their claim for benefits due to changes in circumstances. This can, in turn, lead to concern for the patient, their family or carers, if they experience hardship or frustration in simply trying to negotiate a very complex benefits system. For people already in crisis or acutely ill this can lead to further distress whilst in hospital or through their transition back into the community.

People who have mental health problems that require in-patient treatment are frequently in a state of crisis when they become in-patients or may be in an acute stage of their illness. Having to go in to hospital for unplanned in-patient treatment can mean that people do not have time to organise their finances, welfare benefits, rent or mortgage payments, or discuss any employment issues with employers. Patients being received onto the acute in-patient units at Fieldhead Hospital in Wakefield¹ were experiencing exactly these issues and it became apparent that this was the cause of a great deal of extra stress for those with welfare rights problems.

In 1999, Rethink, a charity that campaigns for people affected by severe mental illness, had made the following recommendations in their response to the Governments Green Paper 'A new contract for welfare' (DFEE 1998):

- The levels of some benefits needed to be increased, particularly the low personal allowances people get in hospital, residential, or nursing care, as the current levels do not provide a reasonable quality of life.
- Assessment of entitlement to benefit and reviews should take account of fluctuating support needs of people with severe mental illness.
- Patients on home leave from hospital should be considered to be on home leave on the first and last day of their home leave as well as the rest of the period of leave.
- The introduction of 'special case officers' to help people with severe mental illness to assist with difficulties with benefit claims, and those arising from inpatient stays.

(Took 1999).

¹ Fieldhead Hospital is located in the Wakefield district of South West Yorkshire Mental Health NHS Trust

A study in Coventry from 2000 - 03 (Royal College of Psychiatrists, 2004), found that 86% of people with mental health problems had difficulties completing welfare application forms. Nearly one third did not claim their full entitlement to welfare benefits.

As a result of concerns expressed by service users, carers, NHS staff, voluntary sector organisations, and Social Services in the Wakefield district, a three year welfare rights project was established in 2003. The project employed a welfare rights worker to provide advice and information on eligibility for welfare benefits claims (e.g. incapacity benefit, income support, Disability Living Allowance, mobility attendance allowance, care attendance allowance), housing, employment and debts advice to patients on acute in-patient units at Fieldhead Hospital. The evaluation of the project was carried out by service user and carer researchers.

Background

A local voluntary organisation, Richmond Fellowship, who undertook advocacy and support work at Fieldhead Hospital, had recorded how many times they were asked about welfare rights issues. Ward staff had also disclosed how they felt unable to answer these queries. Richmond Fellowship approached the Citizens Advice Bureau (CAB) about the problem. They then contacted a number of local voluntary and statutory sector agencies who agreed that a pilot welfare rights scheme based on 4 acute wards should be set up. They were successful in gaining funding for a three year project to employ a welfare rights worker at the hospital.

Alongside this there had been feedback from patients on the units/wards at Fieldhead hospital, Wakefield, during unit visits undertaken by service users, which suggested that some patients were having problems with welfare benefits. Members of the Service User Forum (a group of service users who met regularly to discuss service provision), who undertook the visits, recorded the number of occasions that issues about welfare benefits were raised by patients and took the information to the Patient Advice and Liaison Service (PALS). They were also able to report personal experiences of problems that had arisen. PALS could support this as they had also been asked to deal with a number of welfare rights queries.

Until August 2003 there was no specific welfare rights advice for inpatients at Fieldhead Hospital. Advice was provided on an ad hoc basis by nursing staff who were not experienced welfare rights advisors. In July 2003 a welfare rights worker was appointed to offer support and advice to patients and carers on three acute adult units and a Psychiatric Intensive Care Unit (PICU). In December 2003 one of the acute units was closed leaving the welfare rights worker to work on the remaining two and the PICU. The worker offers advice on welfare rights, debts and other benefits as well as advice on other general problems faced by patients being admitted onto the units. One of the key parts of her role is to reduce the stress faced by people who have benefits, debts and other problems, and ease the path to discharge to make this less traumatic thus lessening the burden of environmental stress. This can be an aid to the recovery process (Coleman, R., Baker, P., Taylor, K. 2000).

Service user and carer interest in the project was extremely high because of their personal experience and knowledge gained through unit visits. As a result they were keen to have an involvement in evaluating the project and the development of the evidence base for hospital based welfare rights advice. The Direct Impact service user and carer led research group was commissioned to undertake the evaluation. The following is a report of the first year of the welfare rights project.

Methodology

In addition to undertaking a literature review, the project team consulted with various key stakeholders including the Social Services Department, the Citizens Advice Bureau, and public involvement staff from South West Yorkshire Mental Health NHS Trust (SWYMHT). Some issues relating to data and the collection of confidential patient information which was not crucial to the project had to be resolved prior to the start of the project.

With the information they had, the project team agreed the objectives for the study and decided to use a survey method (questionnaire). As patients were likely to be going through a period of crisis or acute illness at the time of their initial contact with the welfare rights worker, an additional interview with a researcher was felt inappropriate. A questionnaire in a simple tick box style was therefore judged to be the best form of contact with inpatients on the ward. This method also meant that help was at hand for those patients who had difficulty in filling out the questionnaire.

Using action learning the team designed two staff questionnaires and two service user questionnaires. Action learning was the preferred approach as it involved 'learning by doing', a collaborative/team approach, and empowered the research team undertaking the project. The staff questionnaires were sent out at the beginning of the project and at the end of the first year of the project. The first staff questionnaire was designed to find out what type of welfare rights problems staff were asked to deal with, how competent they felt at dealing with welfare rights problems, and how much time they spent trying to resolve these issues (i.e. time away from nursing duties). The second questionnaire, which was sent out after the first twelve months of the project, was designed to assess staff awareness and use of the welfare rights project worker, elicit their views of the service, and identify whether the service had resulted in benefits to service users and staff.

An initial service user questionnaire was completed on first contact with the welfare rights worker and was designed to identify the type of welfare rights and benefits problems they had and the type of assistance required. Patients were also asked to state how anxious the problem was making them feel. The types of welfare rights and benefits problems listed in the questionnaire were identified through consultation with the welfare rights worker and through direct patient experience. The second questionnaire was given to patients at the completion of the welfare rights worker involvement. This questionnaire asked about the advice they had received and whether this had been helpful or not. They were also asked how the advice had helped and whether levels of anxiety had been reduced.

All those who were patients on the acute units and PICU at Fieldhead Hospital, and who sought advice from the welfare rights worker from the start of the project in August 2003, were invited to take part in the research. The patient group were working age adults aged 18 to 65 years. The inpatient units involved in the project contained approximately 54 beds with consistently high occupancy. The length of patients stay on the units differed but for the purposes of the study was greater than one day. Staff who took part in the staff surveys were nursing staff of all grades working on the acute units and PICU, including agency and supply staff and students, in September 2003 and September 2004.

Project Management

Prior to the start of the project, the project team briefed the welfare rights project worker and managers on the acute units and PICU. The welfare rights worker gave information about the research study to each patient when they contacted her or were referred for the first time. Each participant was handed a letter from the research team with the initial questionnaire. Inclusion in the study was purely voluntary and did not affect the patient's entitlement to advice and support. The majority of people (98.4%) completed the initial questionnaire but a smaller number of people (44.7%) completed the final questionnaire. There were a number of potential reasons for the significantly lower response rate to the second questionnaire. One of the main reasons was the point at which the questionnaire should be handed to the patient. Discharge often happened at short notice and before the welfare rights worker had completed her contact with the patient. Although questionnaires were subsequently posted to patients return was not high. Several different methods of ensuring questionnaires were given to patients prior to discharge were tried including placing them in discharge packs, putting an entry in the welfare rights workers diary, involving nursing staff in giving them to patients, with mixed success.

The project team with the help of a support worker set up a password protected database for the data. The project team have regular monthly meetings to monitor and manage the project. They receive reports and discuss the results and analyse the findings.

Findings

Staff involvement in welfare rights advice prior to project

In order to determine the impact that having a welfare rights worker and project might have on staff, we undertook a survey of staff involvement in giving welfare rights advice. The survey took place prior to the welfare rights worker taking up post and tried to find out how much nursing staff time was taken up with giving benefits type advice. We also wanted to find out how much expertise staff had in giving this type of advice and what types of advice they were being asked to provide.

The survey took place in the summer of 2003 and consisted of a questionnaire given to all nursing staff on the two adult acute units and the PICU. 32 members of staff responded to the questionnaire. 97% said that they had been asked to deal with welfare rights problems. A small number

(16%) were asked to deal with problems on a daily basis. 36% were asked to assist with problems on average once a week, 26% were asked to deal with problems two or three times a week, but 23% were only asked on an infrequent basis. Time spent on dealing with these problems in the working week varied from less than 15 minutes to between 5 and 10 hours.

Nursing staff were asked to deal with problems ranging from advice on housing (94% of respondents), welfare benefits (90% respondents), housing benefit (71%), and debts (58%) to rent and mortgage payments (52%). Although staff identified an equally broad range of advice provided only one respondent said they felt competent in doing so. 47% felt slightly competent in offering advice and 33% fairly competent with the remainder not feeling very or at all competent.

Patients Surveys

1. Types of welfare and benefits problems experienced by patients

Patients on the two adult acute units and the PICU who sought advice from the welfare rights worker were asked to complete two questionnaires. The first was completed during their first contact interview with the welfare rights worker and collected information about the problems they were presenting and the advice they were seeking.

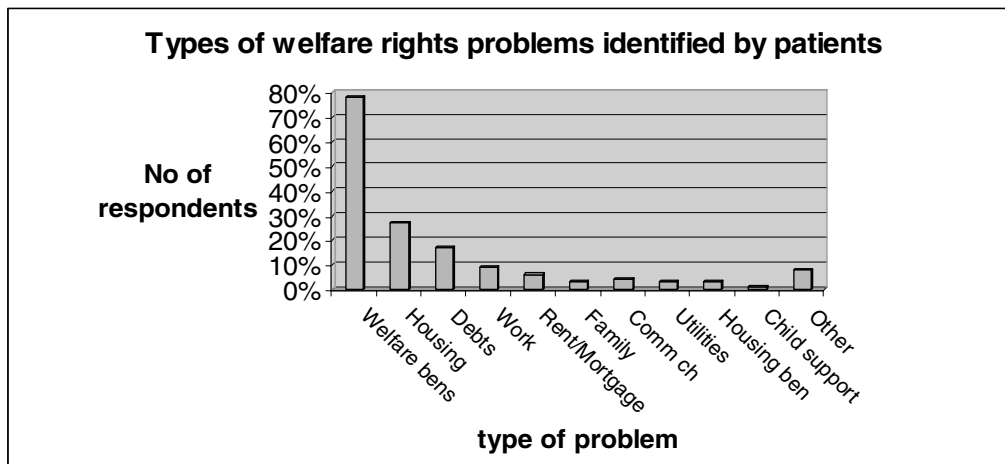
Up to September 2004, the end of the first year of the project, the welfare rights worker had seen 190 people. Of those 187 completed a questionnaire. The problem most frequently experienced by patients on going into hospital involved welfare benefits i.e. difficulties with claiming benefits, benefits entitlements, or problems arising out of their stay in hospital (78% or 146 respondents). However, respondents were asked to identify any welfare rights problems they had and some listed more than one problem area. Housing was a problem for 27% (51) of those who responded followed by debts for 17% (31) (See Figure 1). Respondents were not asked to specify what their 'Housing' problem was so it may have covered a range of problem areas from the need for re-housing or to be housed as the person was homeless (23%), to problems with rent etc. Other recorded problems were concerns about work or employment, rent or mortgage payments, family breakdown, community charge/council tax, utility bills, housing benefits and child support.

The responses related to three recurring and inter-linked qualitative themes of needing benefits advice, clarification of their benefits entitlement, and help with housing or re-housing if there has been a break down in relationships in family or local community. In extreme cases someone may have been technically homeless and without money and would need urgent help to find a place to live after discharge.

Most of the financial advice requested included applying for Disability Living Allowance (DLA) or other benefits, as well as housing benefit, and reflected the recurring theme that people were not clear about what benefits they were entitled to and how to apply. As well as lack of money and lack of clarity about how to apply for benefits there was also a high level of concern about debts. A few people were concerned about employment, redundancy or maintenance of their home and even how to afford to furnish/equip a new home.

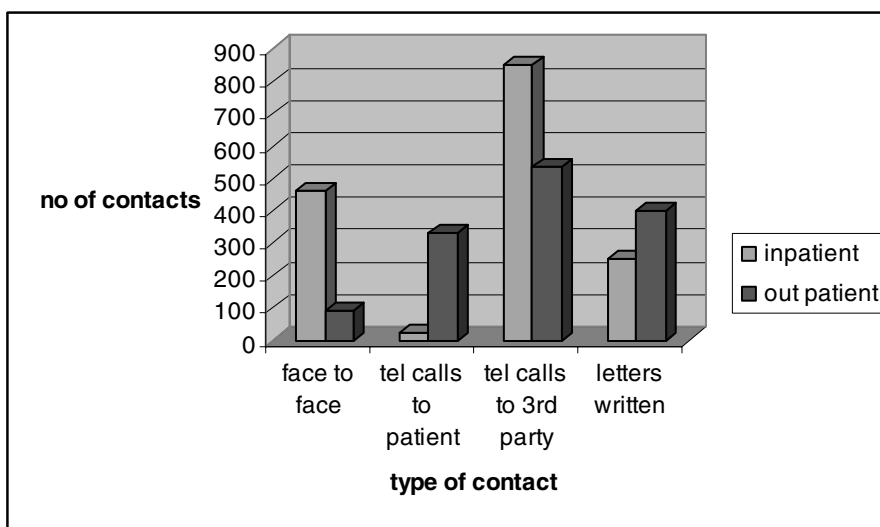
Figure 1 – Types of welfare rights problems identified by patients

N=187



Patients were asked to assess how anxious their welfare rights problems were making them feel. 76% reported feeling ‘very anxious’ with a further 8% ‘fairly anxious’. 78% of those seen by the welfare rights worker for an assessment interview were offered a second appointment. Figures provided by the welfare rights worker of her contacts with patients, up to the end of July 2004, demonstrated the level of contact that was needed to deal with the problems presented by the patients (see Figure 2 below). This included a high level of face to face contact, telephone calls to third parties, and letters. It is also clear from the figures that a high number of contacts (telephone and written contact) took place after discharge suggesting that it was not easy to resolve problems quickly. Time spent on each contact varied according to the nature of the problem and the amount of time available to the welfare rights worker.

Figure 2 - Number of contacts for inpatients and outpatients



Patients were also asked to complete a questionnaire when they had finished their contact with the welfare rights worker. For many this took place on discharge. The number of respondents was much lower than for the first questionnaire at only 85. This may have been due to patients being discharged without the welfare rights worker being told and she was therefore unable to provide them with a questionnaire to complete. Although questionnaires were sent to those who had been discharged many did not return them to the project team. This could have been due to difficulties in filling them in, apathy, settling in at home, and other practical issues that needed to be dealt with.

Respondents were asked what type of advice they had received from the welfare rights worker (see Table 1). 85 people responded to the question. The majority (86%) had received advice on claiming benefits; the welfare rights worker had contacted the Benefits Agency for slightly more than half of the respondents. Half had received advice on housing, rent or mortgage payments or housing benefit. Others had received advice (21%) or help (17%) on sorting out debts. Again the figures reflected the fact that many patients had more than one type of problem and therefore received more than one type of advice. Other types of advice and help given by the welfare rights worker ranged from advice about employment (15%), advice on bills, to contact with the council tax office and companies with whom there were debts. 72% (58) found the advice 'very helpful' and 21% found it 'helpful'. Few found it less than helpful.

*"I found the advice very useful for me to understand things I never knew".
(quote from patient)*

The advice and support helped to gain more benefits or allowance for 49% (41 respondents) and 30% had help which prevented their benefits being lost (see figure 3). This was born out by the Coventry study where 41% of the respondents gained higher rates of benefits after intervention by the Benefit Advice and Advocacy Service. However, it was not only patients who had benefited from the help and support in the Wakefield study, 37% felt that the advice/support had also helped to make things less stressful for their carer or family with 13% reporting that their carer or family had been helped to gain more benefits or allowances. As a result of contact with the Benefit Advice and Advocacy Service, 41% respondents to the Coventry study had more money for food, (32%) for leisure and (27%) for clothing.

Several people made comments on the helpfulness of the advice and support from the welfare rights worker which suggested that she was making it less stressful for respondents. Help with filling out forms and contacting agencies was particularly valued.

"I was not even aware that I could claim benefit. J was a great help in completing claim form and gave me really good advice." (quote from patient)

"J was a great help during my stay in Priory 2. Giving advice on benefits and employment. I cannot thank her enough for the help and advice I received." (quote from patient)

*“J is doing a well needed service for carers and patients. It takes the stress out of a little part of life which would usually make you pull your hair out.”
(quote from patient)*

Table 1 – The advice and support given by the welfare rights worker

N=85

	% and No. of respondents
Advice on claim for benefits	86% (73)
Contacted Benefits Agency	51% (43)
Advice on housing, rent or mortgage payments, or housing benefit	50% (42)
Contacted housing provider or housing benefit office	27% (23)
Advice on debts	21% (18)
Contacted council tax office	17% (14)
Help to sort out debts	17% (14)
Referred for legal advice	8% (7)
Advice on employment	15% (12)
Referral to agency to help with family matters	6% (5)
Advice on repayments	11% (9)
Advice on other bills	9% (8)
Advice on utilities bills	7% (6)
Help to sort out repayments	9% (8)
Advice on dealing with or preventing family breakdown	6% (5)
Contacted company who sent out bill	4% (3)
Advice on child support	1 (1%)
Other advice <ul style="list-style-type: none"> • <i>Sought advice on signing over mortgage to ex-partner</i> • <i>Advice on Legal Aid about suing</i> • <i>Loans or grants</i> • <i>Tax credits</i> • <i>Would like help on council tax, benefits gain more, debts, housing benefit, bills and family breakdown, utility bills</i> • <i>I haven't been paid for three weeks.</i> 	12% (10)

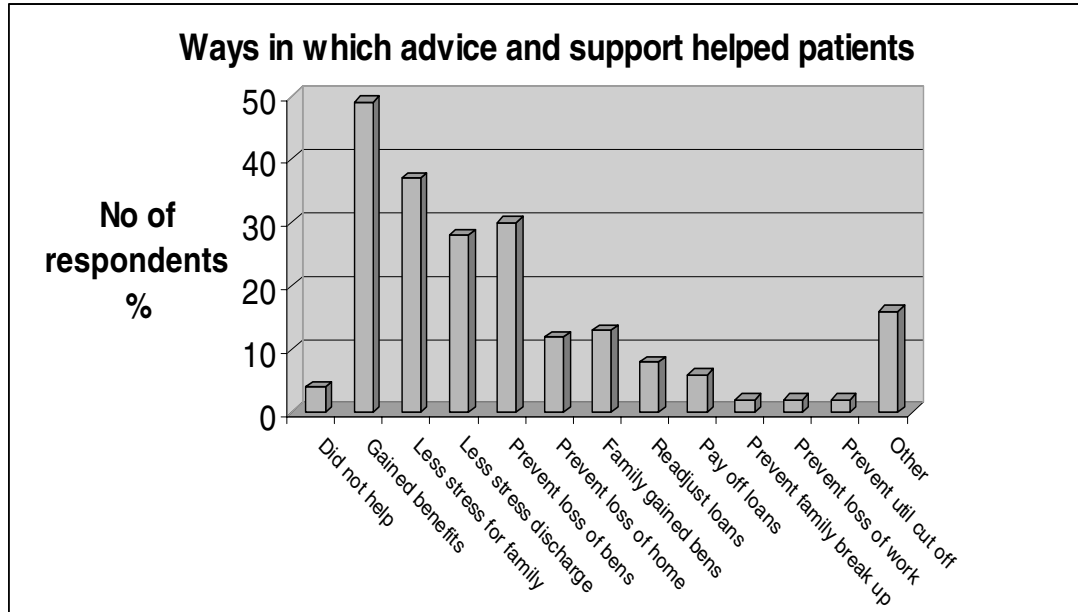
Just over a quarter of the respondents (28%, 22) reported that their discharge and return home had been made less stressful by the help that they had received. 39% said that the help and support they had received had helped to reduce ‘most’ of their anxiety but not all. The continued anxiety felt by the remaining 33% could be due to the fact that not all their benefits/housing/debts or other problems were resolved before discharge, continued illness or other anxieties. This was borne out by the fact that all 85 respondents reported still having welfare rights problems on discharge. 27% of these people had welfare benefits problems, 26% continued housing problems, 18% problems with the community charge and 17% with housing benefit. Understandably, 32% respondents reported still being ‘very anxious’ about these ongoing problems.

“We are now having to pay back (in hours) the wage X was paid while I was in hospital. I get very anxious in case X has to have more time off due to my illness. At the moment I have family with me. I do feel more at ease knowing I have this service to help me with money matters if needed. It is a great service and J was fantastic.” (quote from patient)

“Uncertain what is happening regarding me being rehoused.” (quote from patient)

Figure 3 – The ways in which the advice and support helped patients

N=83



Staff Survey

After the project had been running for twelve months, staff on the in-patient acute units and PICU were surveyed for a second time. Forty nursing staff responded to the questionnaire. All staff reported that they were aware of the welfare rights worker and that they had referred patients to her. They had gained awareness of her through her introducing herself to staff, her presence on the ward, and through posters advertising the service. Staff felt that the worker was well publicised and easily accessible.

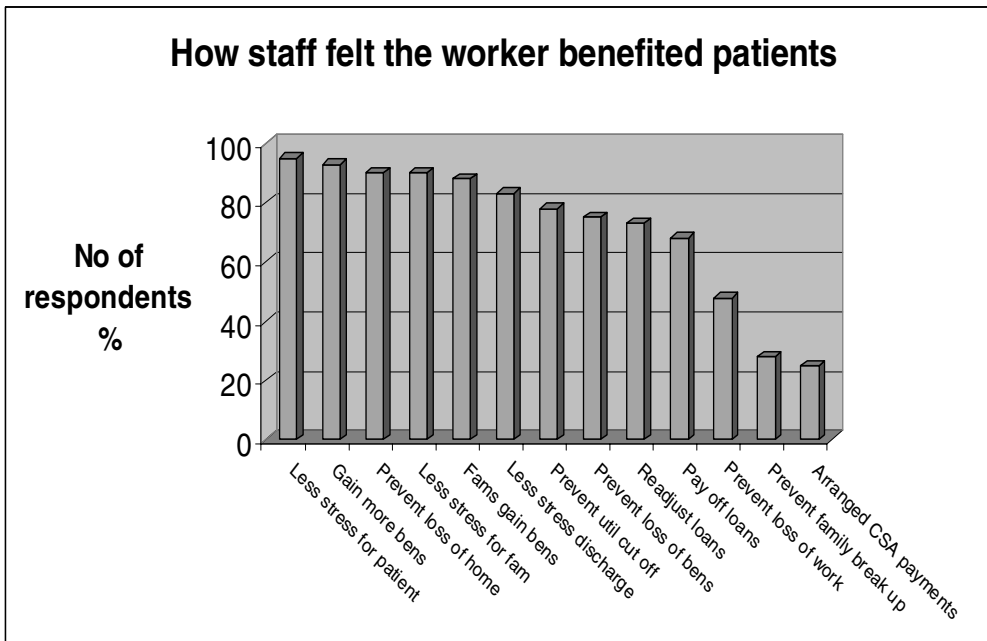
A very high percentage of staff on both units felt that the welfare rights worker had benefited patients by helping patients or their carers or families gain more benefits, preventing loss of benefits and home, reducing stress for patients, carers and families, and making discharge from hospital less stressful (see Figure 4). Importantly, 48% of staff also felt that the welfare rights worker had prevented loss of employment. Staff views are supported by the following quotes:

“Knowing that there is someone to help with non nursing issues makes our job much easier and of course a great help to patients and their families who can turn to people more qualified to assist them in various areas of welfare issues.” (quote from member of staff)

“Makes nursing staff feel more adept in assisting patients meet the needs they cannot deal with and only a CAB worker can. CAB worker is part of the multidisciplinary team and is an essential part of the service we provide to our patients. I believe the interventions of the CAB worker assists in shortening the length of a patients stay.” (quote from member of staff)

Figure 4 – How staff felt the welfare rights worker benefited patients

N = 40



Staff were asked whether they thought assisting patients with welfare rights problems should be part of their role. Almost two thirds (64%) felt that it wasn't. Staff were then asked if they had benefited from having a welfare rights worker on the unit. Three clear themes came out of their responses: the welfare rights worker's expertise and ability to draw on large amounts of information about benefits; reduced workload/less time spent on dealing with benefits issues; this in turn leads to a reduction in stress for nursing staff and more time for nursing duties. 95% of respondents said that the welfare rights worker had freed up their time for other duties. Just under a quarter of respondents felt that the hours of the welfare rights service should be extended to cover the workers leave and for more post discharge work to take place. Other comments by staff stressed just how valuable they thought the service was and how the worker was viewed as part of the team, was approachable, offered expertise and provided an excellent service.

“As a nursing team, we would be absolutely lost if this service was withdrawn. Patients would suffer as money worries/housing are great psychological stressors and a modern acute inpatient service should offer CAB as part of its remit. She needs someone to cover her when she is on annual leave or sickness.” (quote from member of staff)

“I believe she has been invaluable in her input to the overall wellbeing of patients, easing pressures on nursing staff times, allowing more care to be given to patients.” (quote from member of staff)

Conclusions

The welfare benefits system is very complex and negotiating its complexity requires specialist knowledge. People who are experiencing mental illness, particularly those in crisis, can find that the fear of interrupting their claim because of a stay in hospital, or losing their entitlement to benefits, can add to the stress and anxiety of their illness. To facilitate a smooth return to the community and a possible return to employment, sound benefits advice and support is needed as identified by the Sainsbury Centre (2004) and Layard (2005). The welfare rights project at Fieldhead provides welfare rights advice to enable patients to maximise their benefit entitlement and prevent loss of benefits, employment, and family breakdown. The welfare rights project has proved to be a very welcome and successful addition to the acute wards according to feedback from patients and staff who have used the service. In the first year of operation, the welfare rights worker saw approximately 190 people offering them advice and support through face to face contact or contacting other agencies on their behalf. Bearing in mind that prior to the project nursing staff were asked to deal with welfare rights issues, and did not have the working knowledge and time to sort out benefits and welfare rights problems, this could have freed up a significant amount of nursing time. Having the welfare rights worker in the hospital with a separate and distinct role enabled nurses to be able to concentrate more on their nursing role and nurses could also ask the welfare rights worker for advice or refer the patients to them. Staff valued the worker, seeing her as an important part of a multi-disciplinary team, because she offered expertise and provided an excellent service.

The welfare rights worker gained additional benefits or allowances for nearly 50% of her clients and helped carers and families. Her help reduced anxiety for two thirds of the people she advised and feedback shows that patients valued and appreciated the service. They also valued the ongoing help received after discharge and the fact that contact did not end on leaving the inpatient unit. Nonetheless, all the respondents to the second questionnaire recorded some ongoing welfare rights issues highlighting the fact that these are issues that are not easily or quickly resolved. This suggests that there would be value in extending the project to community services. This might in turn help prevent admissions/re-admissions to hospital.

Recommendations

At the end of the first year of the project the project team presented their findings to the welfare rights project steering group, the mental health partnership board for the area in which the project was based, and to managers of the services that took part in the project. They made the following recommendations based on their findings:

- To build on the success of the first year of the project.
- To consider the recommendation to extend the project particularly to cover the welfare rights workers leave and to offer more time for post discharge contact and contact with people in the community.
- To plan for the future funding of the project and to consider the implications if the project was to come to an end.

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