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FACTORS DETERMINING JOB RETENTION AND RETURN TO WORK FOR DISABLED EMPLOYEES: A QUESTIONNAIRE STUDY OF OPINIONS OF DISABLED PEOPLE'S ORGANIZATIONS IN THE UK

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Objectives: **To determine the views of organizations of and for disabled people in order to inform the writing of the British Society of Research Medicines policy document "Vocational Rehabilitation – The Way Forward".**
Patients/Organizations: **A single mailing was sent to 98 disability organizations within the UK.**
Design**: A semi-structured postal questionnaire focused on factors (i) within the National Health Service; (ii) external to it, mainly in the workplace, making it difficult for people to stay in work in the presence of disease/disability, or to find work after losing their job (within the last 6 months).**
Results: **A 30% response rate, with many incomplete questionnaires, was obtained so that 24 complete questionnaires were analysed. The dominant findings concerning the National Health Service were, overwhelmingly, that it was perceived as impacting deleteriously on the work of disabled people with delays to consultation, investigation and rehabilitation and a lack of appreciation of workplace issues. Employers were seen as unresponsive to the needs of workers, with negative attitudes to disability. The changes required in both areas were closely related to these findings.**
Conclusion: **Though the organizations surveyed were not representative, nevertheless there was considerable agreement about the need for both the National Health Service and employers to be more responsive to the workplace needs of disabled people.**

Key words: job retention, return to work, employment, disability, National Health Service.

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INTRODUCTION

A survey by the Health and Safety Executive states that there were 2 million self-reported episodes of illness in Great Britain in 1995. Approximately 65% of these were due to back, neck or limb problems (1). Back pain alone results in 3.7 million working days being lost every year and the costs to employers of work-related ill health and workplace injuries is £2.5 million each year (2).

At present, there are over 6.4 million people with a long-term disability or health problems. This accounts for 18% of the working age population living in private households. Eighty-five percent of non-disabled people are currently economically active compared with only 51% of those declaring disability (3). In addition, figures from the Department of Social Security show that the number of people claiming Invalidity Benefit increased from 805 000 in 1977 to 1.77 million in 1995. This rising caseload is mainly due to people remaining on benefit rather than to an increased number of claimants.

People who find that, as a result of their illness, continuing in paid employment is difficult or impossible may benefit from rehabilitation, in particular, vocational assessment and rehabilitation. Experience suggests that with the closure of employment-related National Health Service rehabilitation units in the UK, rehabilitation commonly focuses not on symptoms and disabilities in the workplace, but deals with the most acute or the most severe disability (4). It may also not be a focus of attention in primary care. Perhaps a more integrated approach is required (5).

Several reports also show that rehabilitation in the UK is "starved of resources" and that existing provision of services is patchy, both geographically and in terms of quality (6). The Association of British Insurers has also recognized that the relevant skills and resources required are delivered in a fragmented way, are poorly co-ordinated and have conflicting agendas (7).

The aim of this study was to ascertain the opinions of organizations representing disabled people about factors both inside and outside the National Health Service that hinder return to work or remaining in work in the face of new illness and disability. The findings were to inform the report on Vocational Rehabilitation published by the British Society of Rehabilitation Medicine (5). The information so obtained may help in the drive to formulate better practice (8).

METHODS

A postal questionnaire covering issues relating to vocational rehabilitation was sent to 98 disability organizations throughout the UK. The semi-structured questionnaire focused on factors related both to the National Health Service and external to it, which respondents thought made it more difficult to stay in work or find work after losing a job

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because of illness or disability. We asked both those in work and those who had lost work in the last 6 months. "In your opinion/that of your organization what are the most important factors that make it difficult for people to stay in work. You may think of factors relating to both the Health Service and elsewhere. Please list (up to) 5 in the Health Service and up to 5 unrelated to it". We also asked "What do you think would make it easier for people to return to work", again for the Health Service and elsewhere. Finally, we asked them to alert us to models of good practice. The questionnaire thus comprised 3 sections. The first related to people staying in work. The second section related to people who have recently lost work (in the last 6 months). The final section related to factors concerning the organization itself including the number of people in the organization, the percentage in work (part-time and full-time) and the percentage experiencing difficulties with completing work tasks or accessing work areas.

The questionnaires were sent out in March 2000 with a prepaid envelope, to be returned within 1 month. Organizations were requested to send brochures and articles (including research articles) that they had found useful. The number of times similar responses were listed by organizations was counted for each question posed. Responses that appeared only once were grouped as "other" subjects.

RESULTS

Ninety-eight organizations were sent the questionnaire. Thirty replied, but 6 declined to fill in the form, so in total 24 organizations both replied and filled in the questionnaire.

Most organizations had between 101 and 500 members. However, the range was wide, from 11–500 (4 organizations) through to more than 5000 members (4 organizations). Three organizations had between 2501 and 4999 members. Table I shows that in 9 organizations over 75% of people were in work and that in 9 organizations 25% of workers had difficulties relating to work, such as completing all work tasks and accessing all work areas.

Although all 30 organizations filled in and returned questionnaires, not all gave appropriate replies to questions and some did not reply to some questions. The results are responses from diverse groups and cannot be considered a representative sample of disabled organizations, nor can we be sure that the characteristics of organizations replying are matched by those who did not reply.

Responses from those still in work

Staying in work. The first set of results relates to those staying in work. Organizations were asked to list up to 5 of the most important factors *in the Health Service* making it difficult to stay in work (Table II). Lack of knowledge within the Health Service of the impact of the disease and disability on function in the workplace was the most common factor. People were perceived as having to wait too long for initial assessment, consultation, effective treatment and rehabilitation. One organization commented that doctors required a more holistic approach towards their patients. Another organization felt that doctors had too rigid ideas about their disabled patients, for example, they were either "fit"; or "not fit" in relation to sickness certificates and there was no "in between" state.

Table I. *Number of organizations of disability: percentages in work.*

	Organizations with percentages of people in work (including part-time and self-employed) (n = 24)	Organizations with percentages of those working who have difficulties relating to work such as completing all work tasks or accessing all work areas (n = 24)
Over 75%	9	1
50–74%	2	3
25–49%	3	2
Less than 25%	3	9
Missing date	7	9

Outside the Health Service, however, employers' attitude toward their disabled employees was listed as the most important factor making it difficult to stay in work. Responses covered many issues, such as bullying, discrimination against employees and not being treated equally to non-disabled employees. Disabled employees felt their employers were ignorant and had negative views about them. One organization felt that the attitude of the employee was also important in determining the degree of difficulty experienced in staying in work. Low confidence levels and low self-esteem on the part of the disabled person were felt to have contributed to this. Another organization felt that employers were not aware of the *Disability Discrimination Act* and that this Act was not followed. Physical barriers, transport problems and inability to access buildings also prevented employees staying in work. Organizations also felt that duties and hours of work made it difficult to stay in work, which was important for those with family responsibilities (Table II).

One organization had developed an employee-retention policy called Disability Leave, a work break during which employees are protected while they adapt to the disability that affects their work. It was designed to enable informed decisions to be made on the disabled employee's work potential that would benefit both employer and employee. These included modifying duties at work, learning new skills, changing working conditions or retraining if there is no suitable role with the existing employer (9).

Return to work. Changes required in the Health Service. The responding organizations had many different ideas on what would make it easier to return to work (Table III). Organizations suggested that the most important factor was to improve rehabilitation services. These should be more readily available, more accessible with shorter waiting lists with fewer delays for consultations and rehabilitation (which should be more intensive). This factor had previously been listed as the second most important factor in making it difficult to stay in work (Table II). They also suggested that removing physical barriers would result in better access to buildings in the Health Service and so could make it easier to obtain services. One organization felt that there should be seamless links between health services and the workplace.

Another organization reported a 90% success rate of return to employment by offering a programme consisting of specific

Table II. *Patients in work, having difficulty.*

	Number of organizations
Factors in the Health Service making it difficult staying in work	
Waiting too long for appointment, seeing consultants, assessments, treatment and rehabilitation	6
Lack of understanding, awareness and knowledge of the impact of the disease and problems it causes	8
Poor access to health services	5
Lack of information and advice for disabled employees	5
Inflexible clinics and hours of service	2
Physical barriers (transport, access to buildings, insufficient adaptations)	4
Other (lack of holistic approach by doctors, lack of funding for vocational rehabilitation, "rigid" ideas held by doctors – "fit" or "not fit" on sickness certificates)	3
Factors external to the Health Service making it difficult for people to stay in work	
Physical barriers, transport problems, buildings inaccessible	9
Employers' attitude (bullying, inequality issues, ignorance, stigma, negative views, discrimination)	13
Lack of information and advice available for employees	3
Lack of knowledge of condition by employer	3
Lack of knowledge of *Disability Discrimination Act* by employer	1
Inflexible duties and hours of work	5
Lack of rehabilitation	3
Lack of knowledge by disable employees of their "rights" and what help is available	2
Other (unstable employment contracts, disabled employee's attitude including low confidence and low self-esteem, poor links between services such as rehabilitation and benefits agency, long waits for appointments, lack of support by benefits agency, lack of career developments and opportunities)	6

modules tailored to individuals' needs. Programmes included vocational rehabilitation, medical rehabilitation and life skills rehabilitation and aimed to regain lost skills, achieve employment and to resume independent living. Assessments are performed by a multidisciplinary team to determine the individual's medical problems, motivation and suitability to the programme. Their progress is assessed at regular intervals during the programme and following its completion (10).

Changes required outside the Health Service. We asked respondents for suggestions and for changes outside the Health Service that could aid return to work (Table III). Unsurprisingly, these were the solutions to the factors making it difficult to stay in work (Table II). The most important suggestions involved changing the attitude of employers, removing prejudice and ignorance and treating disabled employees as equal to non-disabled employees. Removing physical barriers to the workplace and installing appropriate adaptations in premises was also important, as was the need for improvement in the employer's knowledge of the employee's condition and their capabilities in the job. Some respondents felt that government policies to support easy return to work were necessary. Finally there was a request that necessary legal processes should be speeded up.

Responses from those who had recently lost work

The second set of responses related to those who had recently lost work (in the past 6 months). Organizations were asked to list important factors *in the Health Services* that made it difficult for disabled employees to return to work (Table IV). Long waiting times and delays between appointments were again of great importance. Organizations felt that the health services were not responsive to the needs of newly disabled people. Accessing existing services was difficult. They felt that doctors placed too much emphasis on the medical model of

Table III. *Suggestions from patients in work having difficulty.*

Suggestions for the Health Service to make it easier for people to return to work	
Shorter waiting list	6
Improve flexibility of hours of clinics	2
Remove physical barriers for better access to buildings	6
Improve availability of rehabilitation services and more intense	9
Make information and advice more available for disabled employees	4
Other (out of hours consultation, financial support for rehabilitation, seamless links between getting people well and returning to work , recognizing disabled employees as individuals)	4
Suggestions related to factors external to the Health Service to make it easier to return to work	
Improve employer's knowledge of the employee's condition and of what the disabled employee is capable	6
Improve flexibility of job	5
Change attitude of employer (prejudice, ignorance, equality)	11
Improve flexibility of benefits system	5
Remove physical barriers (adapt premises, improve facilities, transport)	7
Retrain disabled employees	3
Other (Government to make new policies and commit to them, speed up legal processes, access to services and new technology, making policies which support returning to work)	4

Table IV. *Patients who have lost work in the last 6 months.*

Factors related to the Health Service making it difficult to return to work	
Long waiting times and delays between appointments	6
Lack of health services and accessing difficulties	5
Too much focus on the medical model of disease	2
Inadequate rehabilitation (lacks intensity)	4
Other (lack of adaptations to access buildings, inflexible hours of services, slow in identifying problems caused by disability and managing these)	3
Factors external to the health service making it difficult to return to work	
Inflexible hours of work and duties	3
Employers' attitude (negative views, discrimination, stigma)	8
Employees' attitude (low self esteem, low confidence)	5
Other (lack of information and advice, lack of understanding by employers, difficulties with obtaining benefits, adjustments within family structure, lack of career developments, poor transition from receiving benefits and returning to work, problems with accessing buildings)	8

disease and the impairments of the employees rather than on their work and social function. Inadequate rehabilitation was seen as the third most important factor. Rehabilitation was neither intensive nor focused. In summary, these responses mirrored those related to job retention.

When asked about factors *outside the Health Service*, the greatest number of respondents said that the attitudes of employers and to a lesser extent, other employees were major factors making returning to work difficult (Table IV). Employers appeared ignorant of their employees and their disabilities; in the workplace there was stigma associated with disability. Poor self-esteem and low levels of confidence in disabled employees also contributed to the difficulty in returning to work. One organization claimed that their members suffered poorer career developments and opportunities for promotion than able-bodied people. Another reported that family responsibilities combined with disability made it difficult to return to work. The adjustments required within the family were considerable, particularly when the work hours and duties required in the job were inflexible.

Factors which might improve the person's ability to stay in work

These mainly mirrored the difficulties discussed above. Many suggestions related to the Health Service were made (Table V). Rehabilitation services needed to be more responsive and flexible, more expert and more tailored to meet individual need. Minor improvements included more counselling sessions within the rehabilitation setting and vocational rehabilitation accessible when the person was still in work. More information and advice were required for disabled employees.

Six organizations cited the need for a reduction in waiting times to see consultants and fewer delays thereafter. Others suggested flexible, better integrated health services.

Outside the Health Service

Organizations felt that changing the employer's attitude was of the highest importance (Table V); they required them to be more supportive, treating disabled employees as individuals and not discriminating against them. Again, flexibility was sought in the job in terms of duties and hours of work. Five organizations felt that employees should be provided with more information on disability and job retention. More knowledge of the *Disability Discrimination Act* was required of employers with adherence to it. Health and lifestyle issues were also cited.

DISCUSSION

This was a small study designed to inform the British Society of Rehabilitation Medicine document "Vocational Rehabilitation".

Table V. *Suggestions from patients who have lost work in the last 6 months.*

Suggestions related to the Health Service to make it easier for people to remain work	
Reduce waiting times to see consultant	6
More education, information and advice for disabled employees	7
Better rehabilitation services (early programmes, specialized counselling)	9
Adaptations to buildings for better access	4
Other (better integration of health services, improve flexibility, more funding for vocational rehabilitation)	3
Suggestions related to factors external to the Health Service to make it easier for people to remain in work	
Improve flexibility of job (hours, duties)	6
Improve flexibility of the benefits system	2
Emphasis on retraining employees	2
More education, advice and information for employees	5
Change employers attitude	9
Other (well-published retention policies, review processes and assessments, working from home, follow the *Disability Discrimination Act*, emphasis on "health and lifestyle" at work itself)	5

It was not intended to be a scientific study and sought opinions from a number of organizations concerned with disability that had not recently been acquired. These organizations are in no formal way representative. For this reason, and because the response rate was low, our findings have limited value. They do, however, give a flavour of the dominant problems arising in the workplace and in the Health Service when the person has difficulty in remaining in work. They do give some leads as to required improvements and indeed a large number of problems both within and outside the Health Service were identified. The findings are unsurprising and are in line with the findings of several reports (6, 7).

It seems that, whereas 25 years ago, the National Health Service had a mechanism for analysing peoples' work potential and grading up their performance towards return to work, it is now rarely able to do this. The Rehabilitation Centres described by Mattingly (11) no longer exist. These centres were specifically aimed at creating a level of fitness compatible with work (5). Awareness of work-related problems within the Health Service is now often absent and well-trodden clinical and rehabilitation pathways to help return a patient speedily to work rarely exist (1).

The speed at which services are received, availability of professional counselling, physiotherapy and "fast track" appointments with consultants are important (12). This stresses the importance of reducing waiting times and having "fast track" services. The Government is now setting targets that are reducing waiting times for consultations and surgery.

In our small study we found that the repeated delays experienced by patients at all stages, diagnosis, investigations and treatment were major hurdles. In addition, too many Health Service personnel were unaware of the work implications of illness, there was a perceived lack of flexibility and intensity in the rehabilitation offered such that there would be difficulty in getting the patient back to work before Incapacity Benefit became available and the likelihood of job retention receded. Research has shown that the Access To Work Programme (13) used to address employment problems was rarely used by hospital doctors so its benefits were denied to patients at a time when they were experiencing work instability (14).

Outside the Health Service, we found similar responses, with lack of understanding, acceptance of disability, poor access and little flexibility and sometimes an unfamiliarity with the *Disability Discrimination Act*. Barriers were not only physical but attitudinal even though other research has shown that employers can be helpful to their disabled employees (15). We know from other studies (15) that targeting the employers' attitudes is required, since discriminatory and unhelpful attitudes and negativity make finding and retaining a job difficult (16).

Some models of good practice provided by our respondents are worthy of mention. One organization had developed the concept of Disability Leave, seeing it as a toolkit for job retention, which included a checklist to help employees think systematically about their situation and initiate change. Others provided grants to purchase equipment and provide tuition fees for training courses.

Stafford (17) recognizes that although there are many surveys of professionals' and employers' views on job retention there is little information at the micro-level for the UK. This survey, although having a low response rate, nevertheless indicates the views of disabled people via their organizations. Their perception differs little from that of insurers, employers' or professionals' organizations; that the response to the needs of employed people in getting back to work is ill-organized and of low priority within the Health Service. The subject is extensively explored (17) and many possible improvements are explored. This situation is in striking contrast to that in the USA and to a lesser extent in the rest of Europe. Lessons can be learnt from many parts of the world.

Thus in the USA the whole system of vocational assessment and rehabilitation is more established and more professional with many securing recognized qualifications. Recently, evaluation standards and performance indicators for the State Vocational Rehabilitation Services programme have been drawn up. There have also been developments in Integrated Disability Management (IDM) which seeks to produce a co-ordinated approach to disability and health needs of workers, however, caused (18).

However the UK health service is freely accessible to all and thus should potentially offer a good basis for an integrated service, even if this requires additional resources from other organizations. The experiences of the Dutch are thus perhaps more relevant.

Holland used to have an extremely high sickness rate, now greatly reduced due to measures initiated by government. Cuelenaere (19) reported on these, comparing the results of related interventions (training and education, work changes, employment services aimed at new employment, sanctions and work incapacity assessments) in 6 countries. The rate of return to work was highest in Holland. This is thought to relate to many factors, not least a flexible partial benefits system which allows people to return to modified work in their own workplace with little delay.

Australia had a health service modelled on the UK's, but recognized that this was associated with an unnecessarily long absence from work. Early intervention was encouraged with reduction of sickness rates by one half in Western Australia. New initiatives included investment in the training of therapists and others who would be providing new services; stimulation of the market for these and creation of the case-manager role (5).

CONCLUSION

There are thus many models of processes and interventions that can be applied to the UK situation. The urgency of so doing is becoming increasingly recognized. It is hoped that the findings from this survey and the BSRM document they formed will add impetus to the resolution of the problems.

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