

BARRIERS AND ENABLERS TO WORK: STROKE SURVIVORS' AND EMPLOYERS' EXPERIENCES

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(1999-2002) from the:



1. THEORETICAL FRAMEWORK

- Social model of disability, recognising 'impairment effects' (Thomas, 1999)
- Also necessarily concerned with illness
Stroke illness - impairment - recovery - disability
- Research process: stroke survivors as partners:
 - Different Strokes identified employment as a key issue for younger stroke survivors
 - Majority of project advisory panel members were stroke survivors
- All Different Strokes members had opportunity to be involved in the research
- 'Work' defined to include paid work and voluntary work

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1. Theoretical Framework
2. Work After Stroke (WAS) project design
3. Stroke survivors' frames of reference
4. Interviews: Stroke survivors' experiences
 - Returning to work for the same employer
 - Getting another job
 - Staying in employment
5. Employers' frames of reference
 - Divergence of perspectives
6. Conclusions

2. WORK AFTER STROKE (WAS) PROJECT DESIGN

1. Focus groups with 5 Different Strokes groups
2. Questionnaire sent to 3000 Different Strokes members
3. Interviews with 24 stroke survivors and their supporters
4. Interviews with additional employers
5. New Different Strokes literature about work after stroke
6. Dissemination of findings and policy recommendations

3. STROKE SURVIVORS' FRAMES OF REFERENCE

- mainly from focus groups

- Rehabilitation system factors: -
Attitudes of doctors, nurses and therapists
- Amount, appropriateness, timing, duration etc of services
- 'Social structural' factors: -
Benefits system; Job market; Transport; Information on retraining; Awareness of stroke in younger people
- Personal factors -
Characteristics: Impairments, fatigue; Qualities
- Family and friends' support
- Employer agency factors

EMPLOYER AGENCY FACTORS

PERCEIVED BARRIERS

- Negative employer attitudes
- Inflexibility
- Failure to implement adaptations to role, hours, equipment etc
- Profitability before employees

PERCEIVED ENABLERS

- Disability Discrimination Act (DDA)
- Adaptations to role, hours or equipment
- Positive employer attitudes
- Alternative employment: self-employment, voluntary work

4. INTERVIEWS

- **Aims:** to explore in depth -
Stroke survivors' and employers' experiences of WAS
Examples of good/poor practice
- **Selection of stroke survivors:** represented total 672
through post-stroke work experience, gender, age
distribution (and under 55), ethnicity, pre-stroke
employment and time since stroke (at least one year)
- **Employment related interviewees**
 - all nominated by stroke survivors:
2 Directors, 8 Line managers, 2 Personnel managers
2 Managers of volunteers
3 Employment advisers
1 Union representative

STROKE SURVIVORS' EXPERIENCES RETURNING TO WORK FOR SAME EMPLOYER (19/24 stroke survivors)

- 'Tone' for return often set during sick leave

Barriers to satisfactory return:

- Being excluded from the loop
- Trying to make contact and being ignored

Enablers:

- Visits from colleagues (without pressure)
- Information re changes at work
- Employer listening to stroke survivor
- Employer preparing for return

RETURNING TO WORK FOR SAME EMPLOYER

Zena is a teacher. After her stroke, she wanted to return on a voluntary basis to see how she got on but was not allowed any contact with the children (on insurance grounds, but this was not explained at the time).

Lucy, an LEA Educational Adviser, had her stroke just prior to a major restructuring. Whilst on sick leave, she was not allowed into her work place, and was not given any information about the changes. Her calls and emails were ignored. On her return a key colleague refused to work with her. She was accused of incapability. Lucy negotiated an agreed reference and then left to be a self-employed educational consultant.

RETURNING TO WORK FOR SAME EMPLOYER

- Wide range of experiences
- Examples in public and private sectors of stroke survivors having positive and negative experiences
- Pressure to achieve targets affected willingness to accommodate stroke survivor in both sectors
- Attitude of line manager important
- Having a senior 'champion' (often someone with prior experience of stroke e.g. in own family) helped
- Case management to assist disabled people in retaining employment proved beneficial where available

RETURNING TO WORK FOR SAME EMPLOYER

Amy worked 25 hours a week for a health authority as a senior district nurse before her stroke. She couldn't do the same job afterwards and applied internally for a new job that would use her professional knowledge and skills.

Amy built up to her previous hours over 5 days a week. However this tired her too much and a different pattern was agreed, working the same weekly hours over 4 days. The manager was concerned initially about not having the post covered every day - but it was working out.

RETURNING TO WORK FOR SAME EMPLOYER

Trevor worked as a team leader on the shop floor in a car factory. The works doctor liased with Trevor's GP and agreed that he would work alternate mornings and gradually increase his hours. On return: new shop floor manager said Trevor must work full time. His management role was no longer available. Union rep told Trevor that the manager had to reduce his staff. Trevor determined to get old job back, so worked full time. Short term sick leave due to stress. Still in job just over a year later but being passed over for jobs on replacement model.

DISABILITY DISCRIMINATION ACT

- One interviewee was planning a case (Trevor)
- One interviewee had brought a successful case
- At least one employer had modified their stance when the DDA was explained to them
- Several stroke survivors had considered taking their employer to an employment tribunal, but had decided not to proceed
- Awareness of DDA was highest in the public sector and the unionised private sector

GETTING ANOTHER JOB (8/24 stroke survivors)

- Very variable time intervals post stroke
- Enablers:
 - Pre-interview discussion
Enabled Carole to explain her emotional lability
 - Champion
Daisy's physiotherapist suggested an increase in working hours, and Daisy left her cleaning job to be a shop assistant - first in a bakery and then in a pharmacy where the manager knew her.
 - Self-employment (4/8)
Supported by an employment adviser, Yannick used his ill health severance payment to fund the purchase of a shop
 - Case management proved beneficial where available

STAYING IN EMPLOYMENT

- Positive employer attitude and willingness to be flexible
- Disabled person's proven ability to do the job
- Job satisfaction
- Positive attitudes of colleagues
- 'Access to Work' paying for eg transport, equipment
- Determination to work

5. EMPLOYER/MANAGER FRAMES OF REFERENCE

- **Negative:** Sees only impairments, 'problems', disabled person as threat to productivity, employee not valued or respected (uncorroborated by employers)
Eg Bank clerk's work post-stroke meant more physical and less mental effort, despite his impairments being physical. Initially marked down at appraisal due to his limp.
- **Mixed:** Provides work opportunity for disabled person but no chance of development.
Eg Former volunteer taken on part-time - mainly photocopying
- **Positive:** Analyses situation to assess opportunity to achieve a good outcome for employee and firm.
Eg Engineer moved to advisory post to utilise his skill, knowledge, and experience. Given home computer to try out work at home. This then extended to other staff.

DIVERGENCE OF PERSPECTIVES

- Employers and employees often differed in their appraisal of the situation (+ve and -ve)
 - several stroke survivors returned to find themselves given different (less advanced) work, without consultation
- Stroke survivors were very aware of employer issues, such as commercial pressures and achieving targets
- Employer ignorance /negativity /insensitivity could be compounded or, to some extent, counteracted by colleagues' attitudes and actions
- One line manager was positive about the particular stroke survivor, yet negative about employing stroke survivors generally

6. CONCLUSIONS

- Complexity of employment issues involving: characteristics of the employer, the job and the employee, available support, organisational dynamics and politics and the employer's legal position
- The DDA can change employers' behaviour, but the considerable effort required to bring a case poses difficulties for stroke survivors
- Where available, schemes to assist disabled people in obtaining/retaining employment were helpful
- The project revealed examples of poor, mixed, good and excellent practice
- Relevance of models of disability?