

Work after Stroke

May 2010

Karen Bryan
Jane Maxim
Lesley Jordan



This presentation

- Facts
- Previous research
- DE project and findings
- Key messages
- DS role

Work:



- Paid, voluntary and study included
- Lots of research evidence that work is important to people's perception of themselves and is +ve for their well being

Facts and Figures:



- Stroke is the largest single cause of severe impairment in the UK (Department of Health, 2001)
- Every year around 49,000 people of working age in the UK have a stroke. (DS website).
- Return to work rates vary from 11-85%.

Study methods:



- Most studies use a medical model- return to work focuses on impairments influencing return to work
- Using a social inclusion model, the focus is on identifying barriers and enablers to work
- Our study focuses on the stroke survivor's own perspectives on factors and processes relating to return to work which previous work has not included.

PROJECT DESIGN



- 1 Focus groups with 5 Different Strokes (DS) groups
- ↓
- 2 Questionnaire sent to 3000 Different Strokes members
- ↓
- 3 Interviews with 24 stroke survivors (SSs) and their supporters
- ↓
- 4 Interviews with 12 employers
- ↓
- 5 Reports and campaigning aimed at government, policy makers etc
- ↓
- 6 New DS literature about work after stroke

STEP TWO: QUESTIONNAIRE



3,000 questionnaires to DS SS members
672 (22%) returned

asked about:

- employment situation before and after stroke
- receipt and quality of acute, rehabilitation and social services
- income/benefits
- whether services, employers, family/friends, transport, job opportunities, training and voluntary organisations helped or hindered work prospects
- individual post-stroke abilities
- demographic characteristics of respondents

STEP THREE: INTERVIEW 24 SSs, 28 SUPPORTERS, 12 employers



Aims: to explore in depth-

- SSs'/supporters' experiences of WAS
- examples of good/poor practice

Selection of SSs: Criteria

- Have worked since stroke, but do not need to be in work now
- Under age 55
- At least one year post-stroke
- (Representative of entire group re ethnicity etc)

28 supporters nominated by SSs

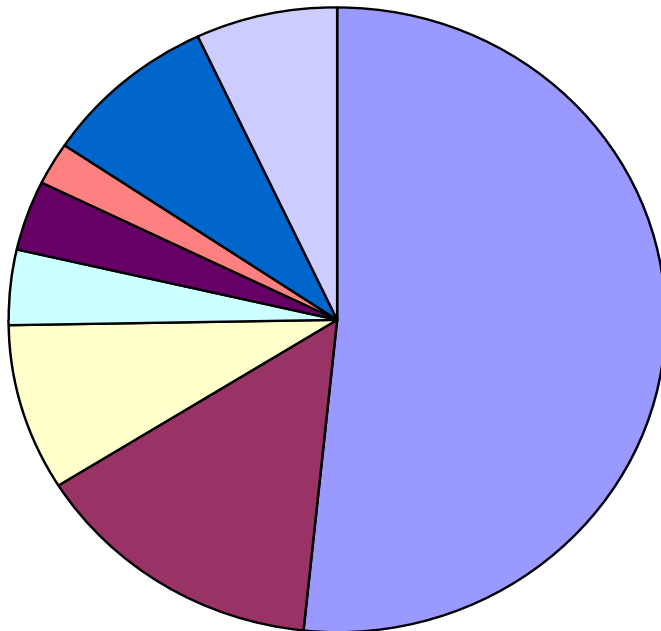
- 7 family members
- 14 rehab workers
- 7 employer supporters

12 employers nominated by SSs

Pre-stroke employment status of 672 respondents



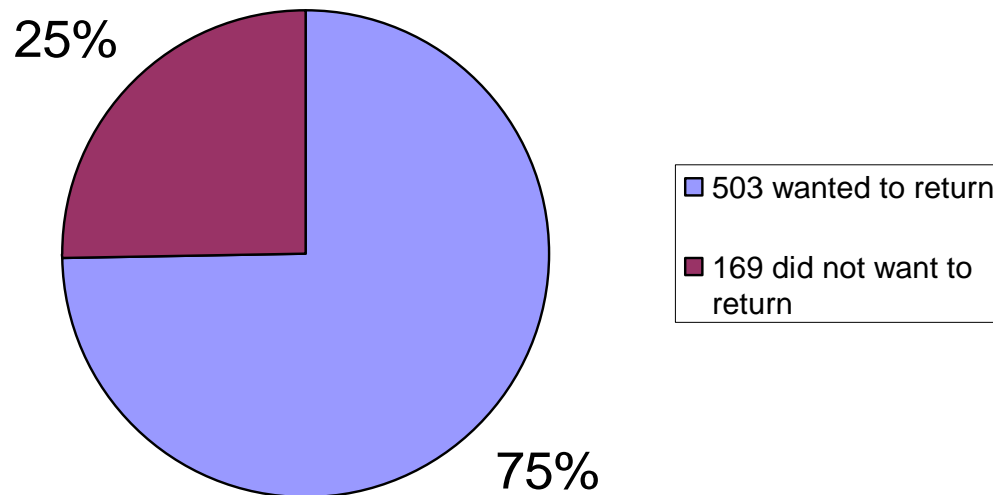
553 (82%) working, studying or looking for work before stroke



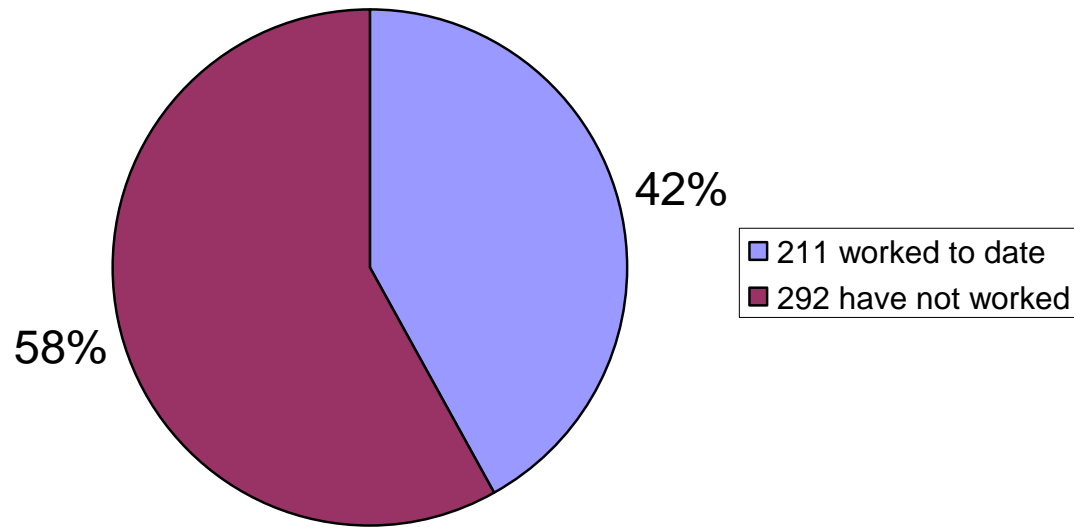
- 347 full-time paid employees
- 98 self-employed
- 58 part-time paid employees
- 25 students
- 25 unemployed & looking for work
- 57 voluntary work
- 47 not looking for work
- 47 retired

EXPERIENCES OF WORK AFTER STROKE

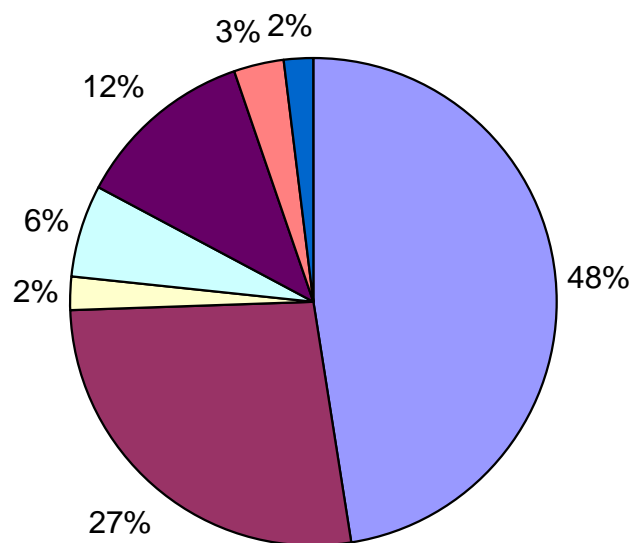
503 (75%) wanted to return to work



211 (42%) returned at some point after stroke

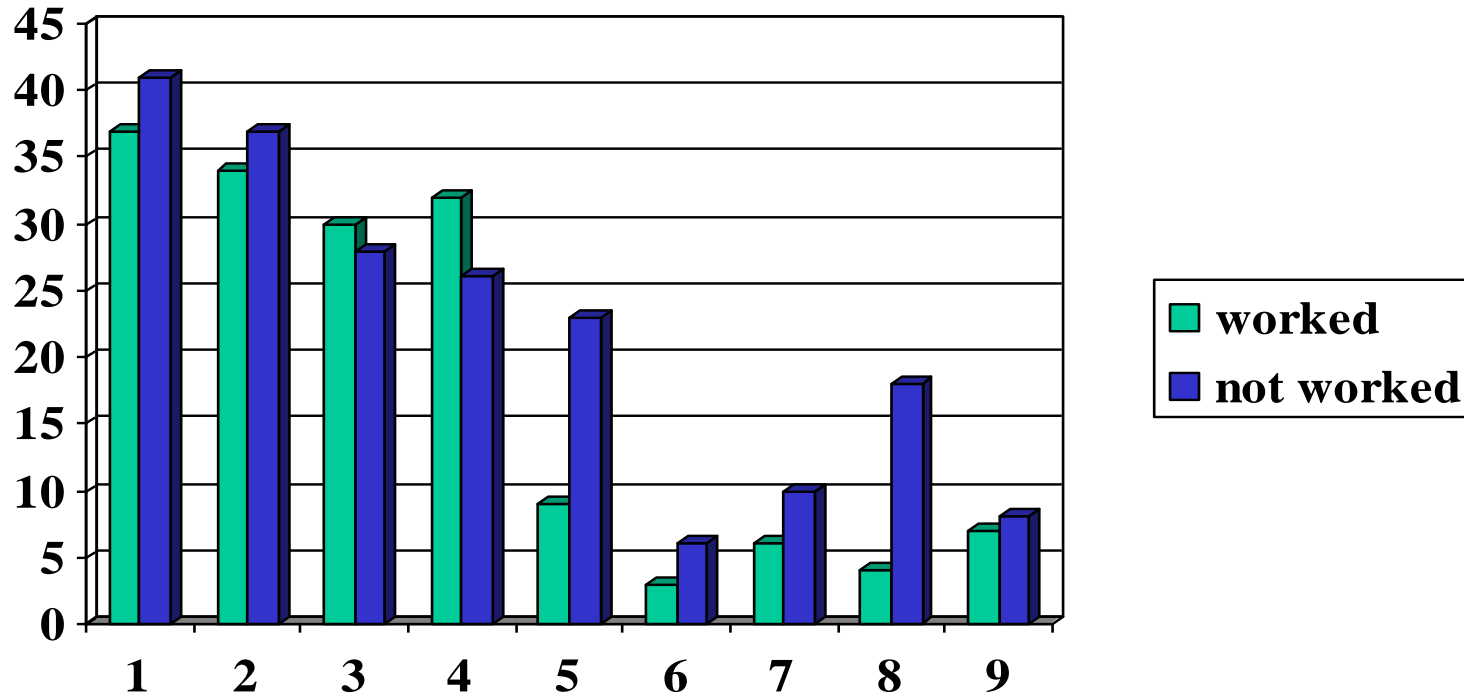


Post-stroke employment status of 503 work orientated respondents



- 239 would like to work but do not feel fit enough
- 135 returned to the same or modified job
- 11 became self-employed
- 31 obtained a different job
- 61 became students and/or did vol work
- 16 are unemployed
- 10 were not working before their stroke but are now

Numbers who have worked/not worked post stroke (/359)



1 Managers/senior officials (78)

2 Professional (71)

3 Associate prof & technical (58)

4 Admin & secretarial (58)

5 Skilled trades (32)

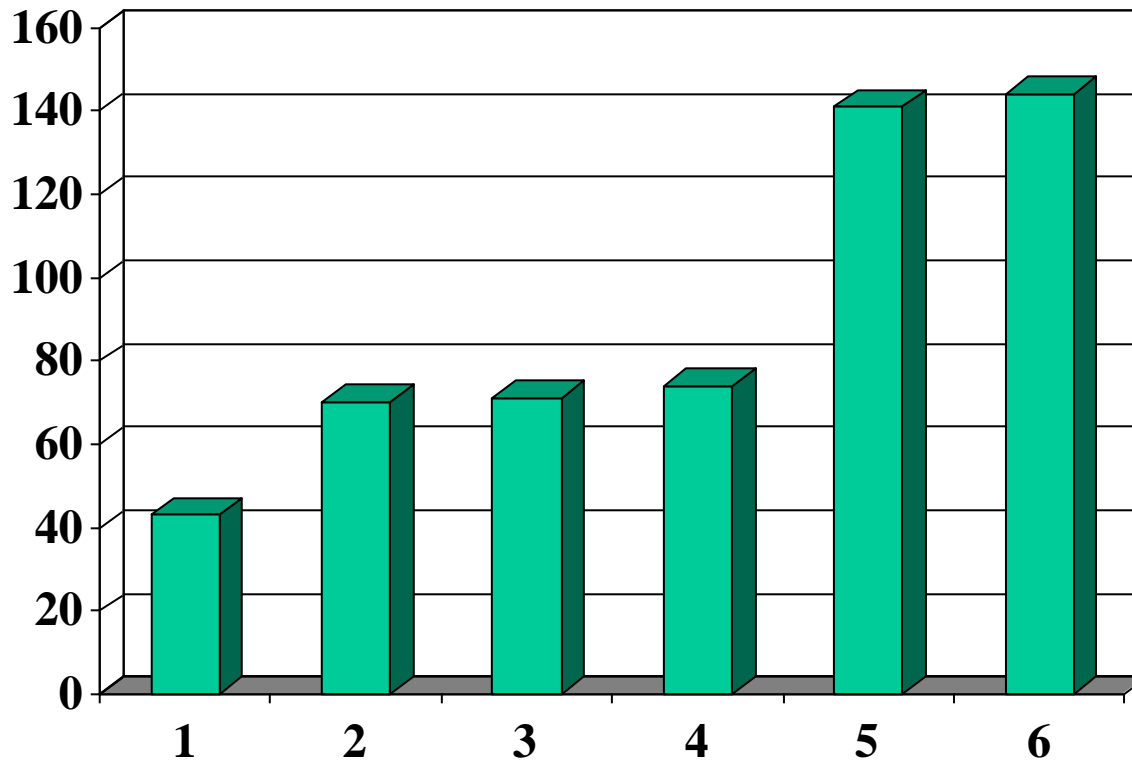
6 Personal service(9)

7 Sales & customer service (16)

8 Process, plant, machine ops (22)

9 Elementary (15)

Reasons for not returning to work after stroke



1 Forced to retire by employer (43)

2 Can't meet expectations (70)

3 Can't drive/use public transport (71)

4 Afraid of losing benefits (74)

5 Not fit enough to work (141)

6 Can no longer do previous job (144)

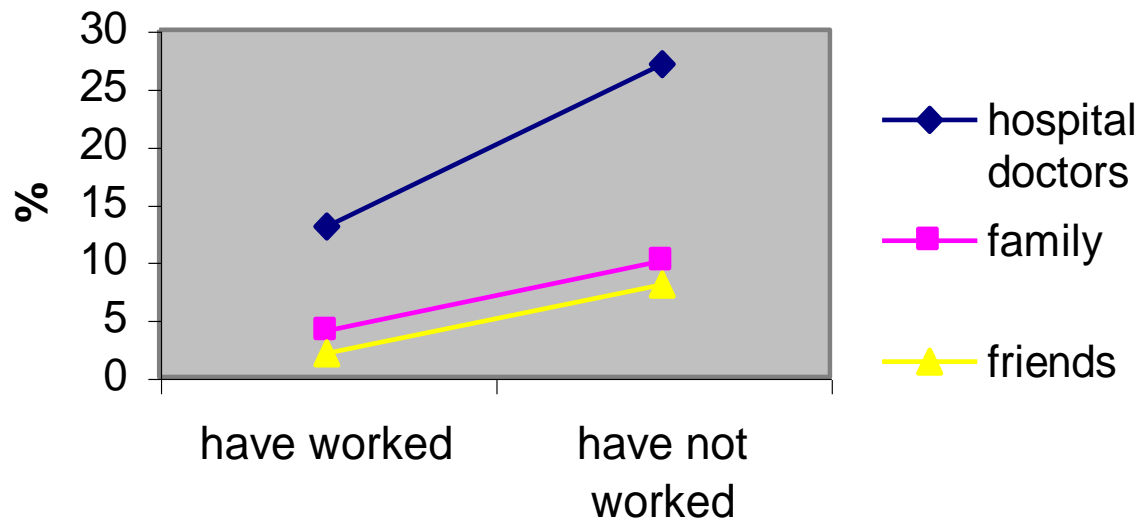
Barriers and enablers



- Key message here is that one person's barrier is another person's enabler
- This is probably telling us that the 'support systems' are there but aren't always easy to access and can be unhelpful
- This places a burden on stroke survivors to 'navigate' the system.

Barriers to Work Prospects

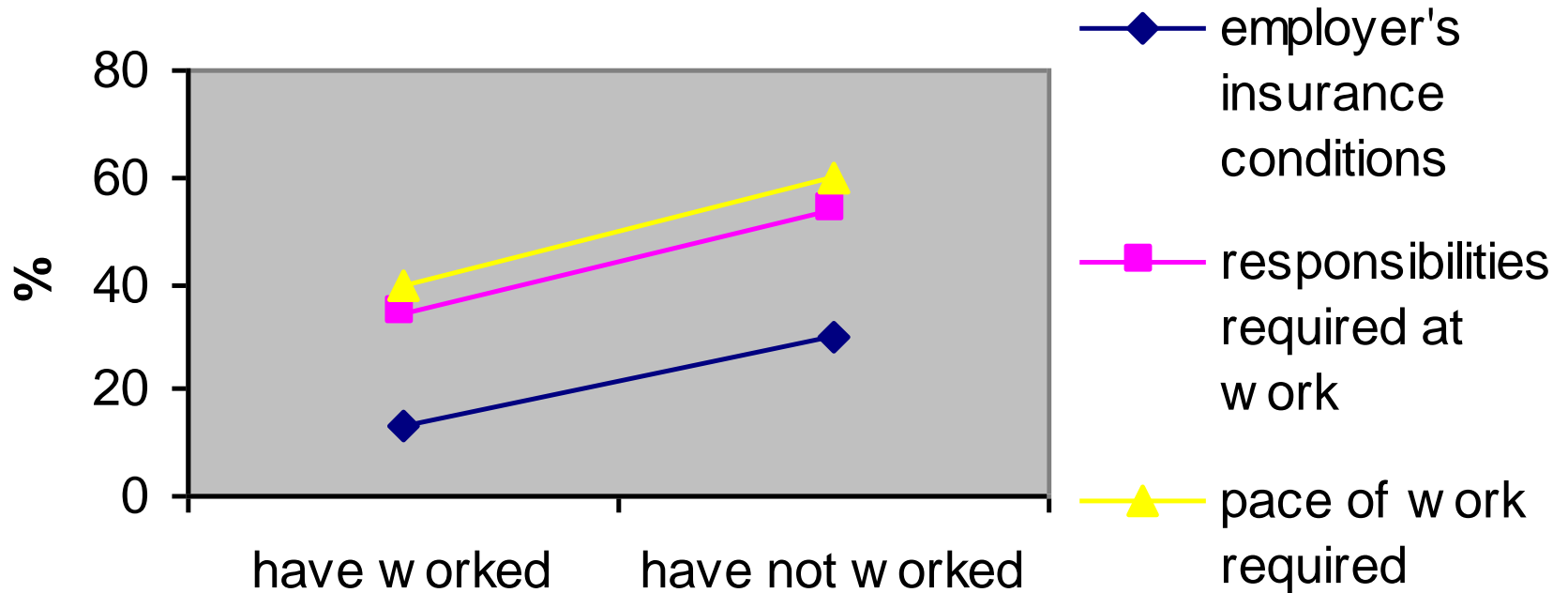
Some differences between those who have and have not worked

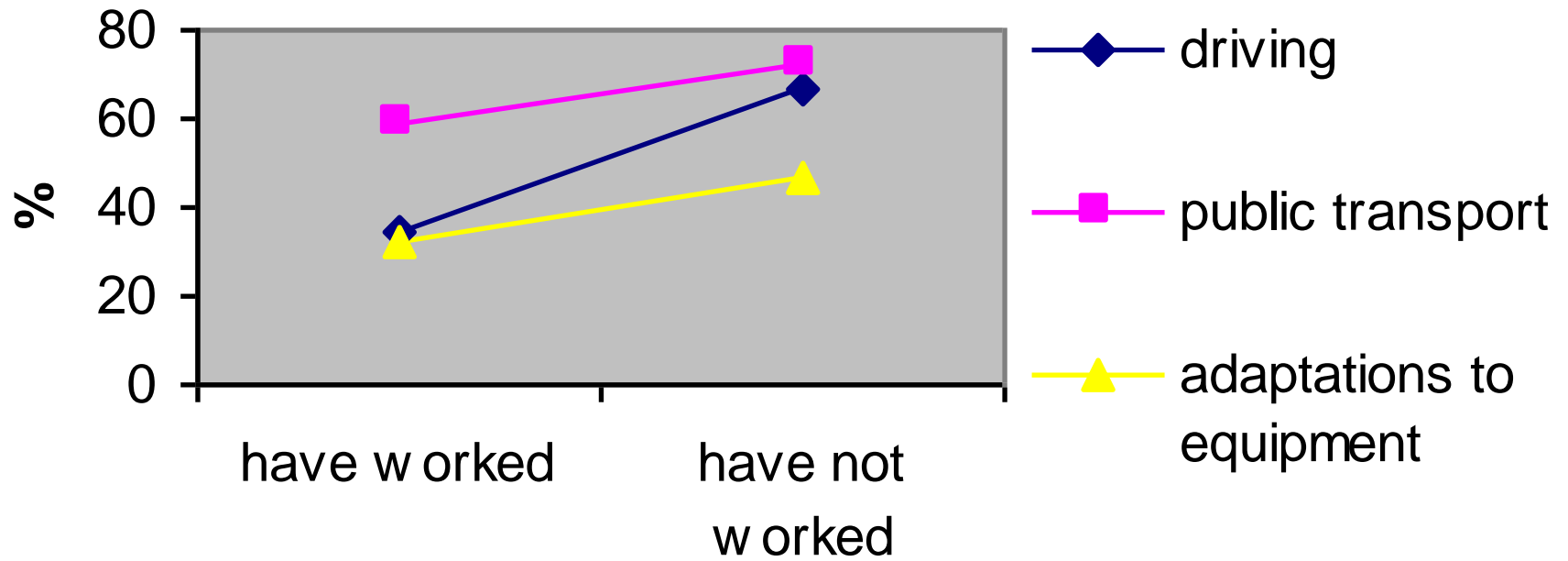


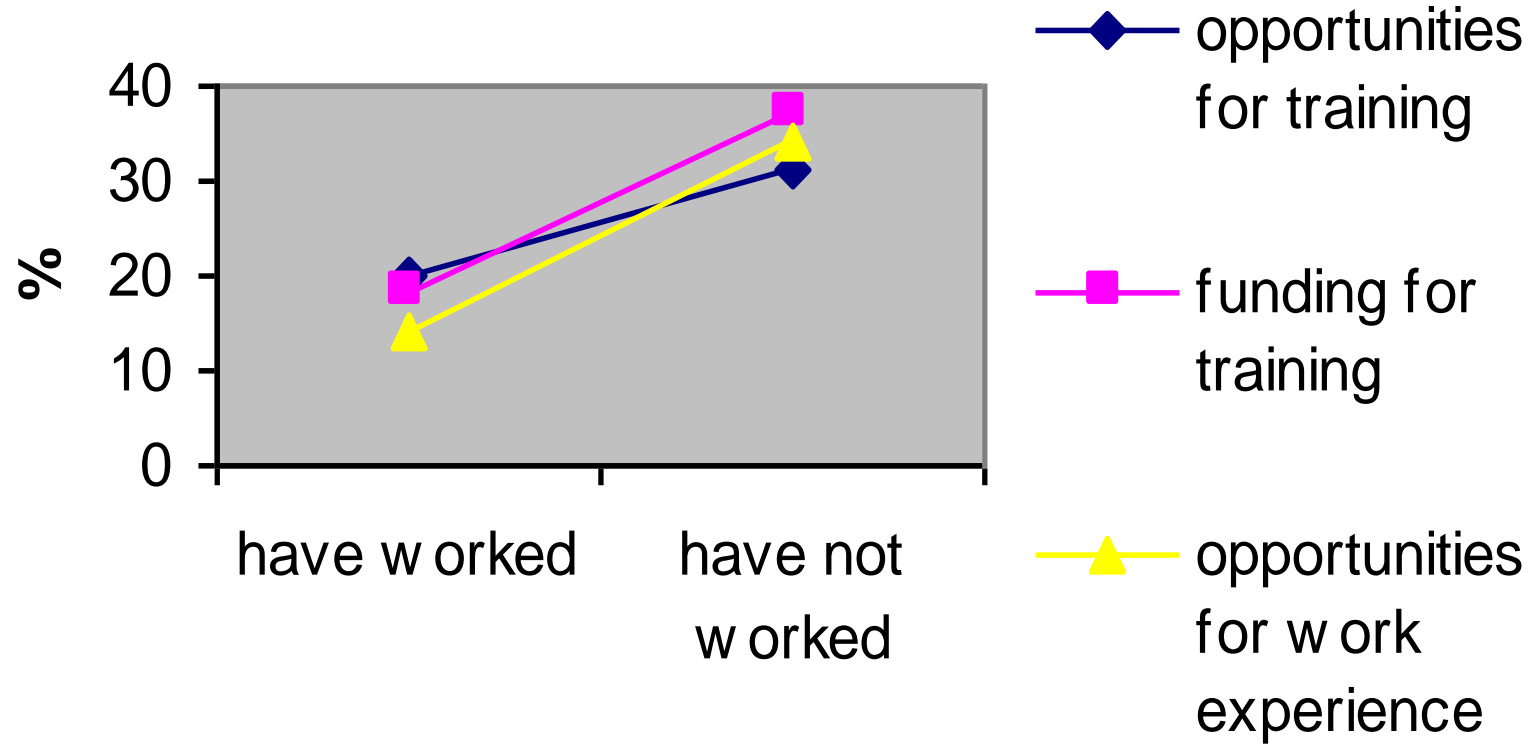
Hospital consultants



- “the consultant said 'just go home and smell the roses', I thought I'm dead, it's only 7½ weeks since the stroke and this guy's written me off... I'll never work again”
- **CAMPAIGN MESSAGE:** don't write people off too quickly and review possibilities for return to work for up to 4+ years







Enablers:

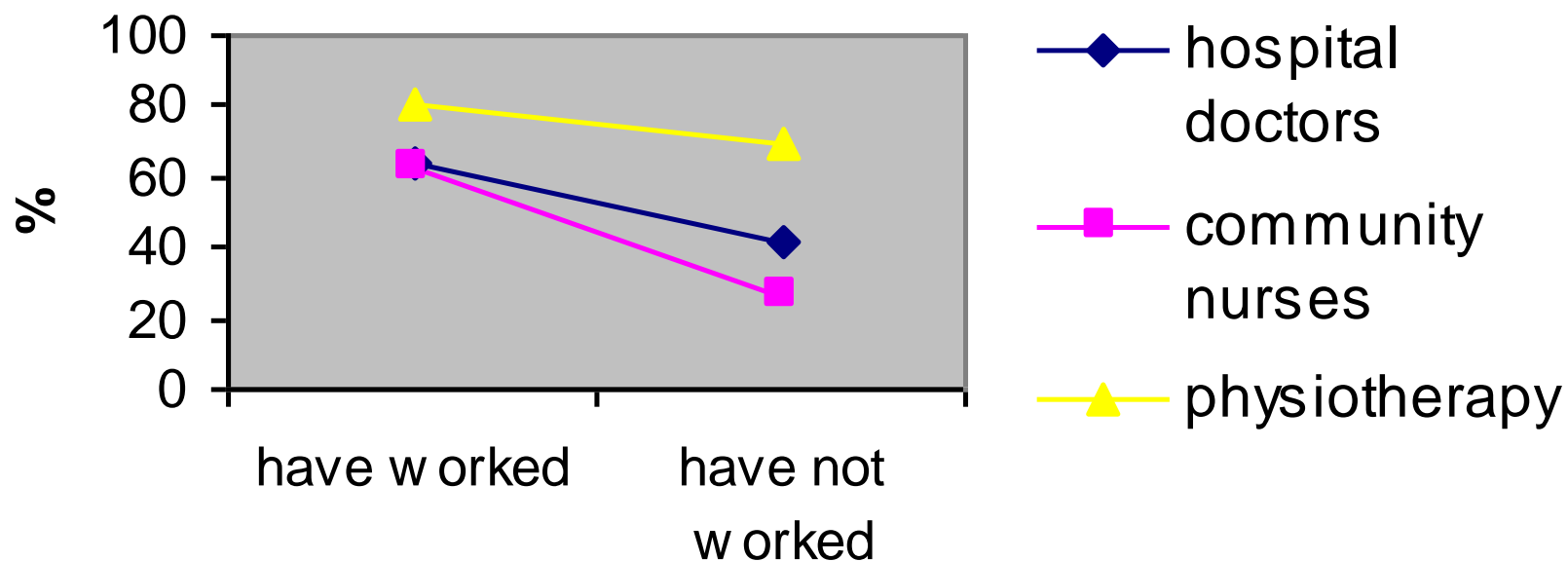


- Same things as barriers
- Essentially reflects where the ‘system’ worked.

Enablers of Work Prospects



Some differences between those who have and have not worked



Campaign point:



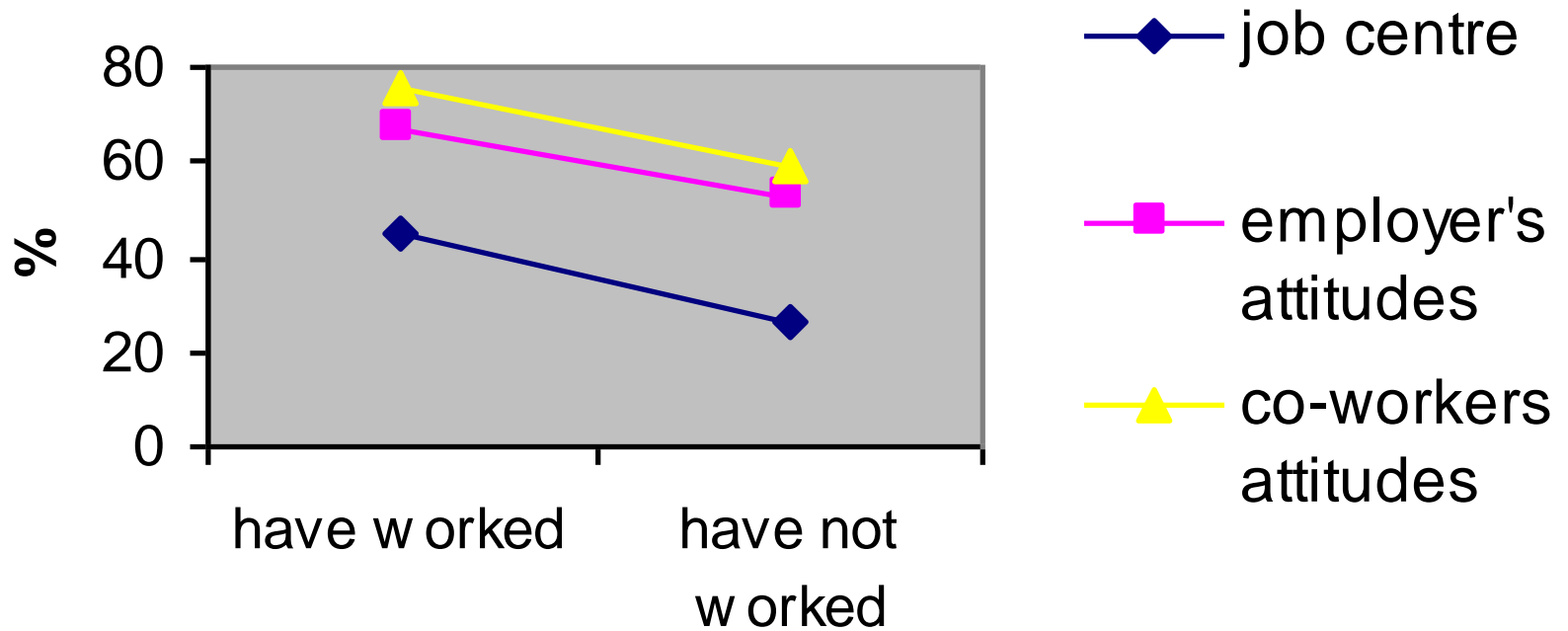
- Information and awareness
- Support to negotiate with employers eg:

“that was my occupational therapist and I think it was a psychologist who came with us as well... It was good to have them with me on that day because they were able to put across that these other things I will need to help me. If I had said that to my boss directly I would never have got any of the things, so I think it was good to have the adaptations through somebody else, because it then said that yes it is needed it is vital to me.”

Rehabilitation



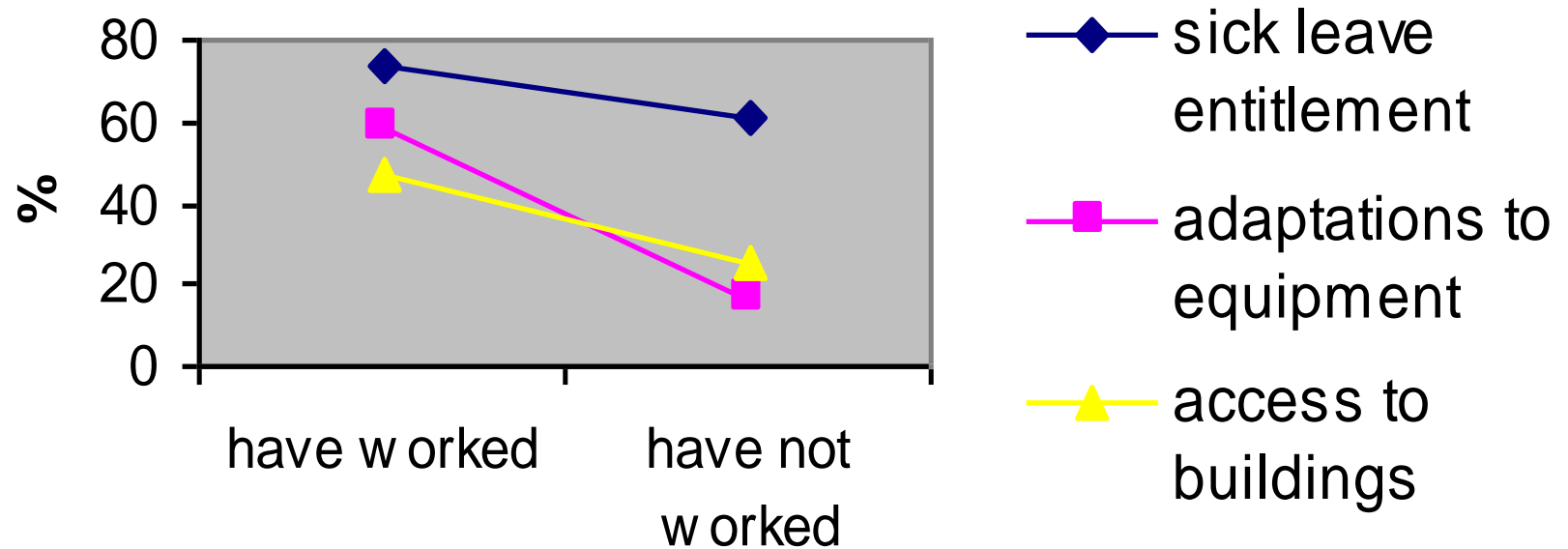
- Generally positive findings- BUT
 - Rehab ends too soon (out of hospital targets)
 - For some SSs there are no opportunities to be referred back for further rehab to promote work e.g., to walk faster, or to get on and off a bus
 - **CAMPAIGN:** access to rehab after the acute stage

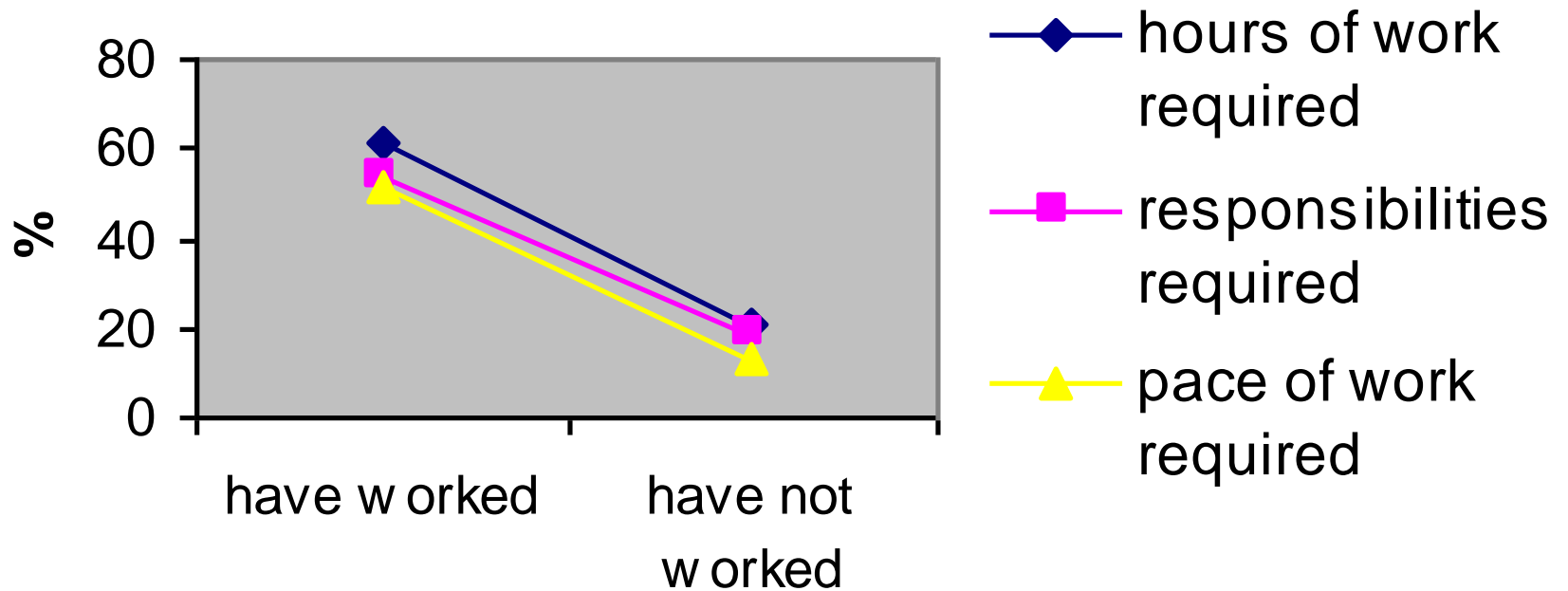


Benefits staff:



- “They are a nightmare, they have complete lack of knowledge and understanding about anybody who's had a stroke”
- “The first disability adviser that I met down at my local job centre was quite helpful and she arranged some interviews for me, but she left, and a new one came in, and she hadn't got a clue...”
- **CAMPAIGN:** awareness raising





Stroke Survivor's need: UNIVERSITY OF SURREY

- Access to longer term or later rehabilitation which considers both the individual's functional problems and facilitates planning for return to work
- Rehabilitation staff who act as key workers in dealing with work matters
- Joint working between healthcare professionals and employers in negotiating and supporting a staged return to work.

DS:



- Continues to campaign
- Supplies key information for free (guidelines targeted for friends and family, employers and health professionals)
- Supplies information by the helpline
- Consulted by the Dept of Health in a stroke strategy review
- Projects to advise on service provision and to explore the use of trained volunteers.