Long-term ill health and the social embeddedness of work: a study in a post-industrial, multi-ethnic locality in the UK

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LONG-TERM ILL HEALTH AND THE SOCIAL EMBEDDEDNESS OF WORK:

A STUDY IN A POST-INDUSTRIAL, MULTI-ETHNIC LOCALITY IN THE UK

Abstract

Against the background of an increasingly individualising 'welfare-to-work' regime, sociological studies of incapacity and health-related worklessness have called for an appreciation of the role of history and context in patterning individual experience. This paper responds to that call by exploring the work experiences of long-term sick people in East London, a post-industrial, multi-ethnic locality. It demonstrates how individual experiences of long-term sickness and work are embedded in social relations of class, generation, ethnicity and gender, which shape people's formal and informal routes to work protection, work-seeking practices, and responses to worklessness. We argue that this social embeddedness requires greater attention in 'welfare-to-work' policy.

Introduction

Welfare reforms under the UK's New Labour and Coalition governments have paid increasing attention to the large numbers of long-term sick and disabled people in receipt of income replacement benefits, which stood at 2.7 million in 2008 (DWP, 2008). In a regime of 'welfare-to-work', people are viewed as capable of overcoming barriers to employment with appropriate support and incentives. Against the individualising thrust of these policies, sociological work highlights the importance of history and context in patterning individual experiences of ill health and benefit receipt. In this paper we utilise concepts from economic sociology to extend such analysis, in the context of experiences of long-term sickness and work in East London – a distinct post-industrial labour market and social milieu. We describe how individual experience of long-term sickness in relation to work is embedded in social

relations of class, generation, ethnicity and gender, which shape people's routes to staying at work, their work-seeking practices and their responses to worklessness.

Harvey's definition of incapacity - the inability to work - as uselessness in the capitalist system (1998: 408) has particular resonance in the contemporary era of 'welfare reform', in which reducing 'dependency' and state expenditure are prioritised. In 2008, the UK's New Labour government set targets to achieve a reduction of one million Incapacity Benefit claimants. Incapacity Benefit, the main long-term sickness benefit, was replaced with a two-tier Employment Support Allowance distinguishing a lower category deemed 'sick, but able to work' whose entitlement to receive additional benefits became contingent upon their participation in employability initiatives (DWP, 2008). This redefinition of entitlements, distinguishing between those who are 'deserving' and 'undeserving' of state support (Bambra, 2008), is part of a wider importation of terminology and policies from the US in relation to 'welfare' – previously known in the UK as 'social security' (Morgen and Masovsky, 2003, Lister, 2013). Britain's policy regime has transformed into one of 'welfare-to-work', combining elements of US-style 'workfare' (work-for-benefit programmes) and European-style labour market activation policies (addressing work experience, job search, skills, training etc) (Bambra and Smith, 2010, Bambra, 2011). In the last few years, policies to counter the 'culture of welfare dependency' have intensified with the Work Programme of the Coalition government (Garthwaite, 2011). Individual entitlements to Incapacity Benefit are being tested through reassessment (covering 1.5 million people by 2014) and assistance to unemployed people is being focussed on 'individuals and their personal challenges' (DWP, 2011: 5). These initiatives are presented by government as 'empowering' to current claimants, who, they argue, have been labelled by the system as 'incapable' and 'abandoned to a life on long-term benefits' (Freud, 2011). However, questions remain about the effectiveness of these policies for all long-term sick people – as reflected in the June 2013

statistical summary from the Work Programme, which found that performance targets for getting new Employment Support Allowance claimants into work were missed dramatically (DWP, 2013: 4).

In a counter-individualistic move, sociological work has suggested the importance of history and context in shaping incapacity and health-related worklessness. Studies have shown that there are much broader political and economic contexts that produce incapacity and health-related worklessness. In some parts of the UK, particularly the North East of England and South Wales, up to a fifth of working-age adults are in receipt of Incapacity Benefit and nearly a third report some kind of long-term limiting illness (Williams, 2010: 183-5). Beatty and Fothergill (2005) have suggested that this high level of geographical concentration reflects 'hidden unemployment' in these areas. Old ports, former centres of coal mining, steel production and heavy engineering, they underwent a dramatic loss of male manual employment in the 1980s when these industries were decimated by the Thatcherite attack on organized labour and break-up of nationalised industry. Beatty and Fothergill suggest that manual workers, many of whom were long-term sick but managed to continue working with the support of their employers, began to claim Incapacity Benefit once they were made redundant. Over the 1990s and 2000s, the profile of Incapacity Benefit claimants changed from one dominated by large numbers of skilled manual workers who lost their jobs due to redundancy, to one comprising a high proportion of people with poor qualifications and limited work experience (Beatty et al., 2009). However, Williams (2010) argues that the geographical concentration of incapacity encapsulates something that cannot be explained only in labour market or biomedical terms; these places and the people who live in them create subjective experiences of ill-health that are more limiting than in other areas.

Discussing the effects of the closure of the coalfields in South Wales, he claims that the 'economic shock' dictated by Thatcher produced a 'cultural crisis' so profound that "the historical relationship of the miners to their work was broken", and the manner in which that relationship was broken is also partly responsible for the subsequent long-term ill-health and incapacity (*ibid.* 193). Other studies confirm that 'welfare-to-work' policies are hamstrung by what Williams calls a failure to understand "what work means, and what forms of work do to people" (*ibid.* 198). In areas with a history of skilled employment in a few dominant industries, characterised by job security and strong trades unionism, the jobs made available by a new economy of low-skilled service sector employment are seen as demeaning (requiring 'novel gender performances') (Smith et al., 2010, Walkerdine and Jimenez, 2012). Moreover, the movement of long-term sick people back to work is hindered by problems of job availability, sustainability and low pay (Joyce et al., 2010, Garthwaite, 2012).

Such studies of incapacity in particular areas have tended to focus on entire regions or specific communities, which are, or are deemed to be, relatively homogenous in their experience of the transformations of the 1980s and 1990s. Here, we contribute to this ongoing research mapping the relationship between (lack of) work and ill-health in specific historically and geographically bounded localities by presenting a situated qualitative study of long-term sickness in East London. We describe how individuals have negotiated their ill-health in various kinds of workplaces in East London, and how they have responded to being incapacitated, drawing out the processes of historical change invoked by the interviews. Not only has the labour market of East London changed over the lifetimes of the participants in our study, but they were positioned differently in that labour market – with respect to their class, gender, age and ethnicity – and those positions have also changed over time.

To understand how individual experience of work is shaped by context, we draw on classic concepts from economic sociology. From Granovetter (1985) comes the idea of the 'formal' and 'informal' organization of work, and the insistence that formal roles and claims are 'embedded' in, or mediated by informal webs of relationships. Whilst Granovetter emphasises the 'personal' qualities of relationships, these are structured by 'social relations'. Burawoy (1985) defines social relations, in the context of factory production, as the relations between and among workers and managers around which the tasks of production are organized. However, we build on Pahl's (1988) broader understanding of all forms of work as being defined by social relations. These extend beyond the factory floor to encompass all the relations of power and domination generated by the capitalist economic system as well as by the principle of reciprocity (as in the examples of work in family businesses which we discuss below) and social hierarchies. Finally, the sociological perspective on economic activity has also been significantly illuminated by the concept of 'social capital', defined by Bourdieu (1986) as the resources that can be accessed informally via social ties based on mutual acquaintance and interests. These concepts allow for an analysis that grasps from an actor's point of view how the options they face when trying to sustain work in the face of ill-health, or trying to access work after being incapacitated, are not atomistic or scripted but "embedded in concrete, ongoing systems of social relations" (Granovetter, 1985: 487).

Research setting and methods

East London presents a different labour market to the North East of England and South Wales, where much of the analysis of incapacity and health-related worklessness in the UK has been focussed. Whilst those localities have historically been dependent on one or two industries and sources of employment, East London had a more differentiated industrial base. Inner East London, being close to the City, was traditionally dominated by food markets and the small sweatshops of garment and consumer goods industries that needed

to be close to their customers. Further out, where there were rail and river links and space for growth, chemical factories, ironworks, ship-building, railway and rail engineering industries were established in the 19th century. The opening of the Royal Docks in 1855 prompted the growth of industries processing imported goods. In 1929, the Ford Motor Company established operations at Dagenham, which became the single largest employer in the area (LBN, 2006). In the last thirty years, the labour market of East London changed dramatically, with the closure of the Docks from the late 1960s, deindustrialisation and the shift to the service sector, and complicated by the redevelopment of Canary Wharf and associated riverside housing from the late 1980s (Rix, 1997). Although London has high labour demand in comparison to the rest of the UK, labour demand in East London continues to be much lower than elsewhere, with job densities comparable to the North East (Williams, 2004: 328).

The social milieu of East London has been memorialised through Young and Willmott's (1957) classic study of Bethnal Green, which depicted a White working class area where people 'got by' through dense local networks. Then, too, East London was a reception area for immigrants. However, by the 2000s the settlement of large numbers of South Asian, Black Caribbean and Black African migrants made for the most dramatic ethnic transformation that has been seen in any part of the UK. Dench et al. (2006) depict a 'New East End', where the earlier dense solidarity had been fragmented by White resentment at the greater social mobility of ethnic minority groups – though ironically, this mobility may be attributed to their exclusion from public and service sector employment, forcing them to reply on their own entrepreneurship. Butler and Hamnett depict contemporary East London as "an increasingly multi-ethnic and multi-class sub-region, segregated in new and complex ways" (2011: 12).

East London has been the site of several studies of long-term ill health. Cornwell (1984) showed how East Londoners' experiences of health and illness emerged from the economic and social milieu of their lives, whilst Widgery (1991) showed the suffering of those who were passed over in the redevelopment of the docklands. More recently, analysis of the 2001 census data showed that rates of long-term limiting illness in East London were as high as in South Wales and the North East (Piggott, 2006: 8), and were higher still among ethnic Pakistanis and Bangladeshis (Piggott, 2006: 16). Rates of working-age adults in receipt of Incapacity Benefit were overall, at 10%, lower than in South Wales and the North East, but far higher than the average for London and the South East region. Whilst no London borough is in the top 20 local authorities for Incapacity Benefit claims among the under forties, East London boroughs rank in the top five for the over 40s (Vaid, 2005: 11).

These studies form the background to current paper, which is based on research carried out between March 2004-May 2006, which explored the relationships between long-term ill health, poverty and ethnicity. The project investigated the material consequences of ill health and situated people's experiences of ill health in wider contexts of family, community and locality. We focus on work, a major emphasis of the project given the policy perception of work as the main correlate, and route out of poverty. The research was carried out in the boroughs of Tower Hamlets, Newham, Hackney and Haringey. To capture some of the diversity of East London, whilst ensuring sufficient data for comparative analysis, we worked with four ethnic groups: White English, Pakistani, BangladesWhi and Ghanaian. These groups have different histories of migration and settlement and different positions in the East London labour market. The lesser education and qualifications possessed by the early Pakistani and Bangladeshi migrants, originating predominantly from the remote and underdeveloped regions of rural Azad Kashmir and Sylhet, differ strikingly from the first

wave of Ghanaian migrants, who were often highly educated and purposively recruited for skilled work.

The research proceeded in two main phases. First, we carried out a detailed preparatory mapping in which we worked with a team of trained 'community researchers', described in [blinded], in four specific localities that we had identified through consultation: one for each the four ethnic groups. We carried out a series of structured activities in each locality including: transect walks (8), mapping/ranking exercises (8), key informant interviews (24), group discussions (8), ethnographic interviews (8) and observations (8). These activities gave us a vivid sense of the history of these localities and how the industrial profile and social make-up of East London had changed during the lifetimes of the participants, and particularly, how it had become ethnically segmented. The historical and contextual understanding that we gained from this phase allowed us to have well-informed conversations with participants in the later phase of the study, and understand what they were telling us about how their individual health-work trajectories were socially embedded.

In the second phase, we conducted in-depth interviews with working-age adults reporting a long-term health condition (57) and individuals living with a family member with a long-term condition (29). Our sampling strategy was largely purposive and made use of multiple access points, with the intention of capturing diversity with respect to health condition, age, sex, migration and employment characteristics. We were generously helped by a number of organizations and key informants who lent us their time and contacts. To focus the interviews, we used a 'life-grid' method to facilitate discussions about the relationships between different events in the life course (see Holland et al., 1999). We began by asking the participants to describe their current state of health, and then asked them to tell us how their illness began and progressed over time. As other life events were mentioned, we

marked them on the life-grid in rows representing different dimensions of the participants' lives (use of health services, household, work/training, family roles, finances, support from friends, support from social services etc). The 'life-grid' method enabled us to locate experiences of ill health and work in specific historical moments, and gave a sense of how the clustering of events in the participants' lives informed their considerations at those times – for example, the sickness of a spouse, or grown-up children starting work. The 'life-grid' was a useful in reminding us to explore issues on which the participants were silent, but it was not followed slavishly and we encouraged participants speak freely about the issues that they saw as important.

The interviews were long and rich, ranging from one to four hours, and conducted in English, Urdu, Punjabi, Bengali, Sylheti, Twi and Ga. Within our research team we had native speakers of all these languages, yet considerations of language and interviewer were highly complex. It was not always fruitful to ethnically match interviewers and participants, since while this sometimes brought shared understandings and intimacy to the interview, it could also constrain the participants from talking about aspects of life history that they found shameful. We have explored these methodological questions further elsewhere ([blinded]). The interviews were recorded and transcribed verbatim. Translations into English were carried out by a small number of bilingual assistants, who were encouraged to retain resonant words and phrases so as not to lose the idiomatic meanings of the original terms (as in the term *halka kaj,* 'light work', referred to below). Using NVivo, the interviews were subjected to line-by-line coding, to facilitate a cross-cutting thematic analysis, and analysis of the participants' trajectories as a whole. However, the analysis offered in this paper derived from juxtaposing the individual interviews with the information collected across both phases of the study. For example, where we have talked about the experience of an individual worker employed at Ford Motors in the 1970s, we have invoked what other participants told

us about how Ford was considered a 'plum job' because of the higher rates of pay, job security and protection the company afforded at that time. The situated picture of East London that we were able to build up allowed us to give a more insightful reading than if we had merely carried out one-off interviews. It was the oscillation between individual stories and the wider histories we learnt about during the preparatory phase that gave shape to the analysis. This draws on the principles of critical ethnography, which involves synthesising the testimony of informants within a broader historical and structural analysis (Wainwright, 1997: 12).

Findings

The findings are structured into two sections. In the first half, we examine individual experiences of sustaining work alongside long-term sickness. In the second half, we examine people's work-seeking behaviours and responses to worklessness.

Long-term sickness at work

In this section, we have grouped the participants into their industrial and occupational sectors, as these presented distinct historical moments in the lifetimes of people in East London and distinct formal and informal opportunities for staying at work. The ways in which individual experiences were shaped by their social location within hierarchies of generation, ethnicity and gender are also illustrated within each of these sectors.

Industrial workers

There was a generation of long-term sick men, and some women, who had earlier worked in the factories of East London but had been out of work for an extended period, in some cases two decades. Long-term health conditions among manufacturing workers were clearly common. Indeed, many of the older participants attributed their current state of ill health to

industrial accidents and years of heavy manual labour. For these older generations, factories like Ford Motors had offered high wages and job protection, including entitlements to sick leave and sick pay which had allowed them to stay at work despite poor health. For example, Sadiq had a slipped disc in 1980 which led him to take two years off work. As he explained, he paid his union subs and private sickness insurance precisely for such an eventuality.

We pay so much money. If after six months you are sick you're entitled to get some money back. That's the private membership. I got it from the Ford. That's why, when I applied for the money, those people were saying 'you're taking long off' and 'it's not very good for us to take so much time', I said 'that's why I paid so much'! Because any time I need it, I can get the money from you.
Sadiq, Pakistani, 60-64 years

Besides these formal entitlements, long-term service also provided what people called 'understanding' with their employers – a kind of social capital, formed of mutual trust and obligation that allowed workers to make adaptations to their job role and remain in work despite incapacity and absenteeism due to ill health or medical visits. For example, when Monica developed psoriasis she had been working at a bag factory for 21 years. She explained to us how she was able to negotiate time off and managed to contain the disruption at work.

We had a laugh, the governors never took a liberty with me. I used to do what I liked basically, I was the only one that got paid when I went to hospital, cause I used to have to go regular like three times a week for the ultraviolet. The governor used to pay me when I went to the hospital. Like he used to go like 'don't tell anyone'. It was a crappy job but it was work you know. They treated me good. As I said, I had a lot of friends.
Monica, White English, 50-54 years

For many in this generation, the decline in their health coincided with the deindustrialisation of East London. The eventual prompt for leaving employment was often the contraction of the industry and the ensuing redundancies and factory closures rather than deterioration in their health status. In a shrinking sector, long-term sick employees were the first to be pushed into taking redundancy, being relatively restricted in the tasks they were capable of doing. Participants explained how they had secured subsequent employment but faced problems in managing their ill-health alongside work in the absence of the supportive formal and informal ties they had previously enjoyed. Monica was made redundant when the bag factory closed down in 1990. She went on to do two short-term jobs where she was 'unable to settle', and she 'retired' in 1994. After returning from his operations, Sadiq could no longer rely on working with one particular supervisor, with whom he might develop an 'understanding', and each time he was moved within the factory he had to renegotiate his job role anew. Eventually, when his plant closed down, he was simply advised to take his redundancy.

That place closed down in 1985. I went to see the personnel manager before I left the Ford. He said we can offer you a job in a different plant. But after the operation you've been getting light work in here because we know you've been working with us since 1969. And we don't guarantee you'll get light work up there. The best way, I advise you, is to take your money, whatever you get. So since 1986, I left Ford.
Sadiq, Pakistani, 60-64 years

For those whose claims to their jobs were personalized, based on 'understandings' they had nurtured over time with their supervisors and managers, the chances of finding comparable new employment were slim. The 1980s was a time when economic restructuring, the attack

12

on organized labour and breaking up of nationalised industry incapacitated long-term sick manufacturing workers, some of whom were never able to find paid work again.

Self-employment and home-working

The majority of the self-employed participants in our study were Pakistani or Bangladeshi, working in small family-run outfits which were largely established in the 1980s and 1990s. For a while, self-employed participants could draw on social capital within the family, to substitute for themselves during periods of ill health. However, the commitment to a business could be highly divergent within families, and filling in for sick family members seemed to be often fraught with tensions and resentment. There was a limit in the extent to which family members were prepared to provide help without reciprocity in the long-term. Yasin, who owned a carpet shop, tried to shift from heavy carpet rolls to working with samples after he developed a back injury, but had to abandon the business after less than a year.

I had nobody else to help me run it [business]. I mean, I've got my wife's uncle, but he's got his own things to do. He was going to open half a day here, half a day there, try to do his best, you know, but I couldn't expect him to do more than that. He's got his own life.
Yasin, Pakistani, 30-34 years

Self-employment concentrated risk onto individuals; something that many felt was worthwhile given the lack of employment elsewhere as well as the support for self-employment that was made available by the government in the 1980s. However, after falling ill, the losses often became unsustainable. Income from self-employment was typically low and unstable, requiring people to dig into their personal savings to cover overheads, take loans on their personal assets to smooth peaks and troughs, and divert working capital from

13

family consumption to tide them through periods of sickness. After four months in hospital, stroke patient Hossein obliged his wife to sell their car so that she could meet her household expenses. With such high levels of personal loss, he eventually had to abandon his business.

I think you're better off working for someone else. Then at least you have a fall-back. Whereas if you're self-employed then you have nothing to fall back upon, it's just yourself.
Hossein, Pakistani, 40-44 years

Several older Pakistani and Bangladeshi women had undertaken home-working in the 'rag trade', undertaking piece-work outsourced from factories as well as jobs undertaken directly for individual clients. Participants reported that piece-work was difficult to combine with long-term ill health as the workloads and deadlines were fixed. Failing to complete the weekly assignment would have to be explained to anonymous middle-men who had many women on their books and no social ties to these home-based workers. Women like arthritic Rabia were released from work, with no recourse to formal union support or law.

She'd be still up working on it four o' clock in the morning. It used to be that kind of pattern for mum... She'd fall behind. She'd tell the workman who used to come and collect the garments, this was a regular thing – oh I'm not ready, come back. But it was like talking to a brick wall.
Azhar, Pakistani, 30-34 years, son of Rabia

Forms of home-working that were more akin to self-employment, such as sewing garments for other Asian women, were more compatible with managing symptoms. Relationships with clients were generally personalised and multi-stranded, and this social capital provided a moral space in which to negotiate a flexible workload. Risham, who had hypertension, said that "if I'm well then I'll do it, if I'm not then I don't, I don't work every day". Participants reflected on the shrinking of the garments industry in East London, which only survived in

any form by cutting costs and relying on ethnic minorities, particularly women, to work on low pay. Mr Udin, who suffered from back pain and had been out of work since the factory he worked for closed in 2003, pointed out that "all the garment factories are closed down now, they've gone overseas, you know, they've gone to Turkey, India, Bangladesh".

Service sector

Service-sector jobs, particularly in retail, were an important element of the employment profile for the younger participants, male and female, migrant and non-migrant alike. This work was insecure and ill-paid, and participants had little investment in their jobs. Mariam, who had episodes of depression and anxiety, expressed a common sentiment about leaving her supermarket job during a period of ill health: "It was only a job, I can get a job anywhere again", reflecting the lack of informal claims based on social capital, as well as the limited formal security, that tended to characterise this sector of the labour market. As McDonald and Marsh (2000) describe, people like Mariam experienced a cycle of 'low pay, no pay', and ill health was just one of a range of factors that caused them to exit employment.

The culture of flexibility embraced by such organisations clearly meant that the employment of long-term sick employees was precarious. Their contracts offered minimal protection for sickness. Many of the participants sympathised with their employers' need to make a profit, seeing themselves as a burden to the productivity of the enterprise. Nevertheless, others fought the system, involving other organizations in the absence of a union. For instance, Zafar entreated local NGOs, solicitors, GPs and his urologist to advocate on his behalf with his supermarket employer over what he described as 'bullying' over his inability to work fast enough in the bakery section.

15

The deputy manager goes, 'I want doctor's letter as well', I said 'fine'. My urologist who done the

surgery wrote a letter down and made it clear that he is a disabled worker, you can't force him to do

heavy work... I went to see the specialist at [local NGO], the special solicitors, and I told them

everything. So then they started writing letters to the store manager and the head office and that's

when they calmed down.

Zafar, Pakistani, 40-44 years

In addition to the large employers, co-ethnic small businesses in the service sector also

employed many of our participants, across all the ethnic groups. In this context, the

availability of support for people working with long-term illness appeared particularly

dependent upon the relationship with employers. Rahman, who was employed in a

restaurant by a fellow Bangladeshi, had secured some flexibility with regard to sickness

related absence. However, others were not so fortunate. Those whose working

arrangements were informal could be promptly released from work, with no recourse to

union support or law. This happened to Patience, who worked undocumented in a West

African-run company.

I quitted because my productivity was low and you know as for the private sector they always want …

working, and that kind of thing. They said I should leave. They think the work was becoming too

heavy for me so I should look for a lighter job. I mean it was a polite way of telling me – 'go'.

Patience, Ghanaian, 45-49 years

Public sector

Public sector employment was more common among our younger participants and among

the Ghanaians, many of whom were highly educated but under-employed. Public sector jobs

offered protection and higher rates of sick pay, and the relative institutional stability of the

organizations also provided job security. They also offered non-manual work which could be

more easily reconciled with long-term health conditions. Those in skilled positions tended to have employers who were more proactive in seeking out adaptations to allow them to remain at work. Clarissa, who worked in human resource management, lost a substantial amount of hearing as a result of meningitis, but was helped back to work by technological adaptations like text-phones and by her supportive employers:

Before I went back to work the director of the branch where I was actually sent round a note to everybody saying, obviously we'd given him an update on my situation, and he said something like 'Clarissa is returning to work on such-and-such a day without any hearing at all while she waits for the operation, it's important', and he stressed the importance that 'you don't make her feel alienated in any way or form'.

Clarissa, White English, 30-34 years

However, not all public sector managers were keen to retain their sick employees. Kwame, who had been working with the government for twenty two years, had to take early retirement when he became sick. He was asked to take time off work, and when he took a long time off, he was advised to apply for early retirement and give up on his full entitlement.

The ministry would not say because you can't work we have retire you, because that means they have to give you two thirds of your pay, so I was advised to apply for early retirement, which I did.

Kwame, Ghanaian, 60-64 years

As illustrated by the contrasting cases of Clarissa and Kwame, accessing formal entitlements like sick leave, sick pay and adaptations at work were contingent on supportive relationships with managers and employers. Moreover, when public sector workers were threatened with

internal reorganisations and efficiency drives, as happened to Mary below, long-term sick

individuals were under greater pressure to take voluntary redundancy or early retirement.

The contract was only for six months, which I wanted to continue. But then I was most of the time

sick, so they decided not to renew my contract. They said they couldn't renew my contract because I

was most of the time sick. My son was too, so I was taking a lot of leave, taking him to the hospital

and looking after him. I took them to court because of that, because I felt they were being

discriminatory because if I was sick, I didn't intentionally get sick.

Mary, Ghanaian, 45-49 years

This section has illustrated how individual locations in the East London labour market were

varied, and experiences of being long-term sick at work depended on the formal claims that

their employment afforded them at that particular historical moment. However, people's

ability to mobilise formal entitlements to sick leave, sick pay and workplace accommodation

of incapacity were often contingent upon facilitative informal, social ties. Furthermore, the

participants' life histories illustrated how labour market restructuring had brought important

changes to both formal and informal work-based relations, with a trend towards increased

insecurity and greater obstacles to remaining at work while sick for many over time.

Work-seeking practices and responses to worklessness

Consistent with other studies, the majority of our participants expressed a desire to work, at

least in principle. Work was felt to offer benefits over and above providing an income,

including routine, an opportunity to get out of the house and meet other people, and

distraction from the symptoms of ill health. Nevertheless, participants experienced huge

challenges in finding work that was compatible with their ill health, skills and experience in

East London, which is characterised by low overall labour demand and a low wage economy.

Finding work compatible with ill health

The ex-industrial workers wanted to do what they called 'light work', which they believed they could reconcile more easily with their health conditions, but felt that 'light work' was unattainable for them. They recognized that the labour market had changed drastically in the last few decades and fitted poorly with their lack of qualifications and prior work experience. In other cases, the participants felt victim to age discrimination. This was felt particularly by the older Bangladeshi men, who were heavily reliant on co-ethnic networks for finding employment and largely restricted to the restaurant sector. These men recognized that their chronically ill and ageing bodies did not fit the bill for service jobs which they saw dominated by young people. Abdul, who had back pain and angina, explained that;

I am still looking. If there is any *halka kaj* (light job), then I would do it... at my age I don't think I can work in a restaurant. People want young people who look smart, speak well with the customers.
Abdul, Bangladeshi, 50-54 years

At the time of fieldwork in 2005-6, the participants were already affected by the policy drive to get long-term sick people back to work. Among the participants who had experienced these schemes, there was weariness at 'fighting the system' and bafflement at the rules and regulations of the social security system. Again, the common theme was the difficulty in finding work that participants were equipped to do and that could accommodate the incapacity implied by their ill health. Martin had impaired mobility due to a road accident, but lost his Incapacity Benefit after he had been reassessed by the 'DSS doctor' (responsible for medical assessment of incapacity claimants) as fit-for-work. He was sent to an employment agency to take part in a scheme for the long-term unemployed, and placed in a

workshop making double glazing units. However, he was later forced by the agency to give it up. His experiences reflect the target-driven nature of 'welfare-to-work' providers;

They put me on this scheme for long-term unemployed run by [employment agency]. I was swallowing painkillers like nobody's business and I did about a month's worth of painkillers in a week and a half. My doctor went mad at me! They then kicked me off for not being fit enough to work. And the dole, 'oh you're not fit for work therefore you're not entitled to Job Seekers Allowance'. And then you're not disabled enough to be on Incapacity Benefit. You get bounced between the two.
Martin, White English, 40-44 years

Brian had previously run a shop selling decorator paint, but suffered from mental illness. He had completed government training courses many times, and was disillusioned with all these schemes and pessimistic about his chances of finding work.

There's not a lot out there for what I can actually do, other than if I wanted to start my own business again. But I know for a fact there's no money out there to start my own business. I don't want to go through all that rigmarole with the courses again. I've done it already three times. I've had the experience with two businesses. I don't see why I have to go through it all again just because that's the law and that's their rules.
Brian, White English, 40-44 years

Our female participants were generally more positive about job-focussed activities than the men (a similar finding to Tackey et al., 2006). Those who were involved in volunteering felt good about these activities and saw them as helpful and generally self-improving, although not necessarily employment-focussed or likely to result in paid work. Some reconciled their health conditions with work by doing courses which gave them opportunities to re-invent

themselves and learn skills. This was more likely for the educated young women. Fatima's young age allowed her to try several different things and gain motivation;

I am doing this to learn a skill by myself, for the future if I work…. I have equipped myself with the knowledge. Last year at [name of college] I did a course in hair and beauty. I can't do hard things. In my mind I feel good when I do things that I enjoy. It makes me feel less ill. If I sit idle at home I only worry about my health…. I only think about the pain and feel that the pain is getting worse.

Fatima, Bangladeshi, 30-34 years

Frustration and alternative identities

There were strongly gendered and generational dimensions to the participants' frustrations with the labour market. For the younger male participants, it was clear that worklessness was a huge challenge to their sense of self, as they judged themselves against the standards of breadwinner masculinity. Martin could not bear to be financially dependent on his girlfriend;

It's the feeling that you're sponging off her and you're... you have to go out because she wants to go out and she has to pay for everything so you're in the situation of say either agreeing to let her pay yet again or refusing to go out [pause]… Yes, worthlessness, uselessness.

Martin, White English, 40-44 years

In contrast, some of the older male participants, particularly the Bangladeshi and Pakistani men, appeared to find it easier to adopt a non-working, elder identity (*barhe* in Urdu or *morubi* in Bengali) that did not challenge their sense of worth. These participants were found to spend their time at the mosque or engaged in community activities, with some justifying their withdrawal from work in terms of giving opportunities to the younger generation.

My boys started work so then I said fine, I'll leave the job. I thought alright, I'll take early retirement [from Ford] and I'll pay it back by working for the community instead. So like now when people come to the community centre, sometimes I drop them home if they haven't got any transport, I get job satisfaction if you like... All I need is clothes, a roof over my head and *roti* (bread) two times a day.

Abdul, Pakistani, 55-59 years

Many of the women prioritised looking after family rather than struggling to find work that they could perform alongside ill health. There was wide variation in orientations to paid work, illustrating the enmeshing of ethnicity, class and gender in the construction of work-based identities. Among the Ghanaian and White English participants, female employment was the norm. For some of the Pakistani and Bangladeshi women, however, particularly those who were older, poorly-qualified and had come from rural areas of Pakistan or Bangladesh, paid employment was not very relevant to their current lives. Often, they derived a sense of being hard-working and productive through their work in other arenas, such as bringing up children and caring. For some of the younger, more highly-qualified Pakistani and Bangladeshi women, work was part of their idea about a successful life. However, the combined gendered expectations of household maintenance and caring – which were very important to their self-identities – and the limitations associated with ill health made paid work difficult and many opted not to seek employment. For example, Amina found juggling paid and domestic work alongside her heart condition too exhausting, and left her position as a classroom assistant.

When I came back from the school it was very tiring for me. It was difficult for me to rest because I had kids, household work, cooking, cleaning, it's too much to do for me. That made me tired and it affected on my heart as well. I thought it was easy but no, if it's taking too much, that's making me sick. That's not good. I don't want to take any risk on my health.

Amina, Pakistani, 35-39 years

Discussion

Whilst 'welfare-to-work' policies increasingly emphasise the 'personalised' and 'conditional' nature of government support to long-term sick people who are outside the labour market, in this paper we have shown that history and context matter greatly to the question of incapacity and health-related worklessness. In this study, long-term sick individuals speak to us from their location in a labour market that is highly segmented by class, generation, ethnicity and gender. We see them as social actors engaged in ongoing relationships, who try to sustain work by drawing on their formal claims to sick leave, sick pay and modifications to their occupational role, as well as their informal claims based on 'understandings', or the qualities of relationships between workers and employers (Granovetter, 1985, Bourdieu, 1986). Social relations come to the fore; both the all-important power relations between and among workers and employers (Burawoy, 1985), as well as the power relations generated by principles of reciprocity and social hierarchies (Pahl, 1988), which surfaced in the many accounts of conflict faced in the workplace by our long-term sick participants. Particular contexts matter more than others. Within the lifetimes of the study participants, the labour market in East London has changed. Moreover, people are located differently within the labour market, and their positions in the labour market also change over time. There is a certain irony that as the discourse of welfare-to-work increasingly emphasises the individual and the personal, the wider labour market appears to have become less personal, at least for those at the lower end, so that informal claims are harder to establish and people struggle to build new forms of social capital that could replace the older forms and help them secure employment.

Our account of East London presents a different picture of embeddedness to earlier work in South Wales and North East England. In those regions the loss of skilled manual work in a

23

few dominant industries characterised by job security and trades unionism produced a 'cultural crisis' (Williams, 2010) in which the relationship that men had with their work was broken so profoundly that it produced widespread incapacity. By contrast, East London appears as a much more segmented and differentiated labour market in which many have remained in a cycle of 'low pay, no pay' rather than being completely incapacitated. For those who are out of work long-term, there were strong frustrations with the labour market which had a gendered and generational dimension. Many of the women in our study preferred their family roles over having to juggle domestic and paid work alongside the limitations associated with ill health. Similarly, we found that many of the elder Pakistani and Bangladeshi men sustained a sense of worth through a non-working, elder identity, illustrating the important diversity that exists in terms of 'what work means' and 'what work does to people' (Williams, 2010). Nevertheless, the idea of a 'cultural crisis' was apparent with the older White British men, many of whom had been out of work for an extended period, felt ill-adapted to the new economy given their poor qualifications and past work experience, and were exhausted and degraded by the 'rigmarole' of the welfare system.

The findings discussed in this paper show that social embeddedness should be given more attention in the formulation, operation and evaluation of 'welfare-to-work' policy. Whilst many long-term sick people are frustrated about their inability to secure work, the obstacles they face are intimately bound up with their social location; their networks of formal and informal relations and what these afford. Furthermore, work is not always good for wellbeing, especially where job quality is poor and multiple other roles compete with paid work. Activation policies aimed at 'overcoming personal challenges' and 'removing disincentives' will have limited success in getting long-term sick people into work in a low wage, low labour demand economy – as reflected in the most recent evaluation of the Work Programme, at the time of writing (DWP, 2013). As Williams (2010) has said, there is a need

to resist ideological closure when it comes to the discourses of 'deserving' and 'undeserving' that have undergirded welfare reform. A contextualised, historically-situated approach, such as that offered here, is much needed if we are to adequately understand and respond to ill-health related worklessness.

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