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## PRE-PUBLICATION VERSION

### **Ill-health in the family: the intersection of employment and caring across households from four ethnic groups**

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#### **Abstract**

The employment rates of both disabled people and those from minority ethnic groups are subject to substantial UK policy attention. In this paper we set out to enhance understanding of the relationship with the labour market for those living with long-term illness and their family members. We explore the role of family caring responsibilities and ethnicity in shaping patterns of employment participation. We do this by investigating the experiences of those from four different ethnic groups and using a mixed qualitative and quantitative approach.

#### **Introduction**

The employment rates of both disabled people and those from minority ethnic groups are subject to substantial UK policy attention, in a context of increasing employment targets. A recent Green Paper (DWP, 2007a) has confirmed full employment as the central plank of welfare policy and that being ‘in work’ means being ‘better off’. Policy emphasis on the positive benefits of work, for the economy and for reducing individuals’ poverty risks, has been accompanied by empirical investigation of the precise nature of barriers to employment. However, relatively little attention has been paid to the situation of those both with long-term health conditions, and from minority ethnic groups. Despite recent research on disability and ill-health within the family and its relationship to labour market participation (McKay and Atkinson, 2007; Atkinson, Finney and McKay, 2007), the intersection between ethnicity and ill-health and the ways in which they are lived out within households deserves greater attention. In this paper we set out to enhance understanding of the relationship with the labour market for those living with long-term illness and their family members. We explore the role of family caring responsibilities and ethnicity in shaping patterns of

employment participation. We do this by investigating the experiences of those from four different ethnic groups and using a mixed qualitative and quantitative approach.

We first set the context for the discussion of our findings by outlining the employment agenda in relation to both disabled people/those with long-term health problems and minority ethnic groups. We then briefly describe our research project before outlining the extent to which individuals' lives and family and employment experiences were structured by ethnicity and long-term ill-health.

A recent DWP research report on disabled people's employment emphasised the clear employment deficit of disabled people, but also drew attention to the variation in chances of being in work according to both nature and severity of the condition and other personal and family characteristics (Berthoud, 2006). Overall, the chances of being in work for more than 16 hours per week were less than 30 per cent. Analysis of those with long-term limiting illness, also show substantial employment deficits.

Since the 1990s increasing attention has been paid to reducing the numbers of people claiming incapacity benefit (IB). The premise of welfare reform has been that it is possible to distinguish between those capable of work and those who need support; and that many of those currently in receipt of IB can and should be – and would benefit from being – in employment. The 2006 Welfare Reform Green Paper (DWP, 2006) clearly laid out this position and proposed the reformulation of IB into Employment Support Allowance, which would have more stringent criteria for the 'support' element and would remove some of the disincentives to re-employment that have been assumed to go hand-in-hand with receipt of IB. These proposals were confirmed in the 2007 White Paper and the new benefits will come into existence in 2008 (DWP, 2007b).

However, the distinction between incapacity and capacity for work is unclear both conceptually and empirically. As Berthoud pointed out, there is no point of severity at which there is a step-change in employment chances; and, on the other hand, many of those who might be considered to have relatively minor forms of incapacity nevertheless face reduced employment chances. The inter-relation of 'capacity' and changing labour market conditions – both in terms of overall job opportunities, and

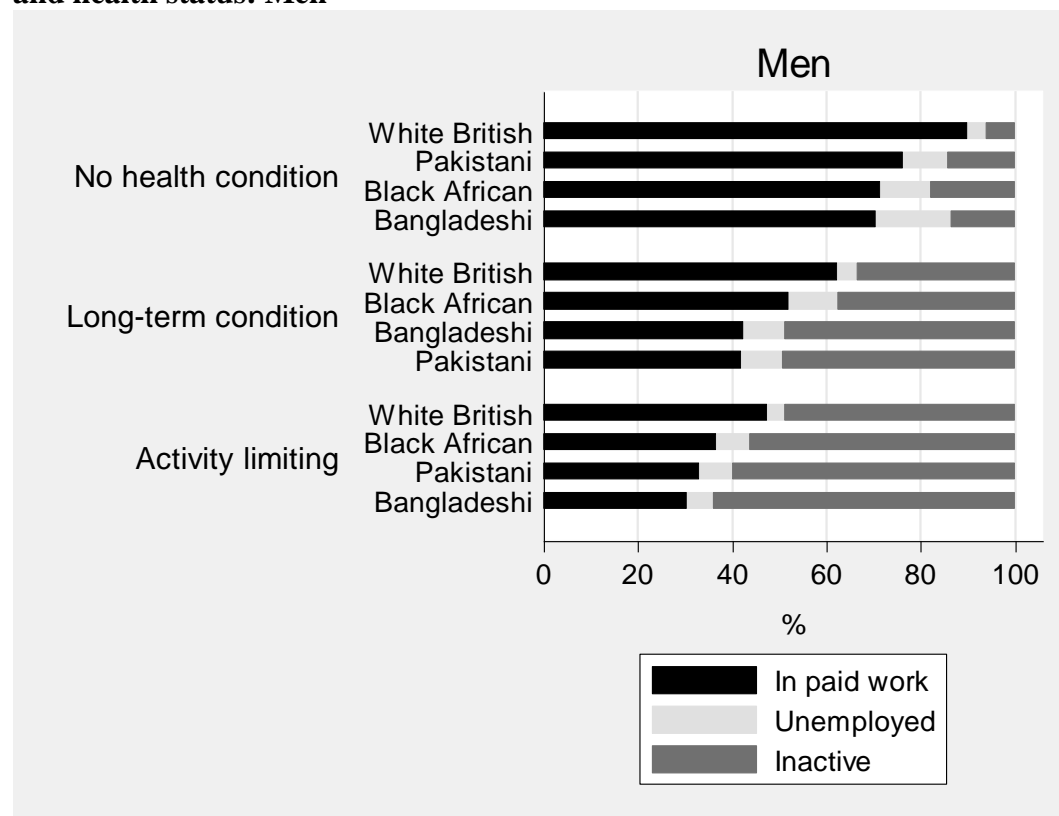
also the changing nature of work and skills presents a challenge for those determining whether work is a realistic option for any given individual, particularly in terms of making appropriate evaluations over time.

There are, of course, a number of factors influencing employment chances among disabled people over and above severity of disability, and one of these is ethnicity. Minority ethnicity has been consistently associated with employment penalties, in particular for those of Pakistani and Bangladeshi ethnicity. Recognition of the large variation in employment rates across ethnic groups is now widespread (see, for example, Figures 1 and 2, below). And since 2003, there has been an explicit policy agenda to reducing the employment gap between majority and minorities.

Following the conclusions of the Performance and Innovation Unit (2002) / Strategy Unit (2003) *Review of Ethnic Minorities in the Labour Market*, a cross-departmental Ethnic Minority Employment Task Force was established to address the reduced employment rates of minority ethnic groups. The Task Force is chaired by the Minister of State for Employment and Welfare Reform; and the Department for Work and Pensions has a PSA target to close the employment gap between minorities and majority. A recent *Opportunity for All* report (DWP, 2006b) highlighted particular measures to engage with minority ethnic job seekers and their partners; and barriers to ethnic minority women's employment specifically are gaining increasing attention, particularly with the recognition of the numbers of households where all adults are out of work, and of the very low rates of economic activity among women from some minority groups.

One of the reasons for higher inactivity rates or greater proportions of workless households among *certain* groups is high rates of long-term ill health. This is especially the case for Pakistani and Bangladeshi men, even though this does not account for their employment disadvantage (see Figures 1 and 2), and neither does minority ethnicity account for the employment disadvantage of disabled people

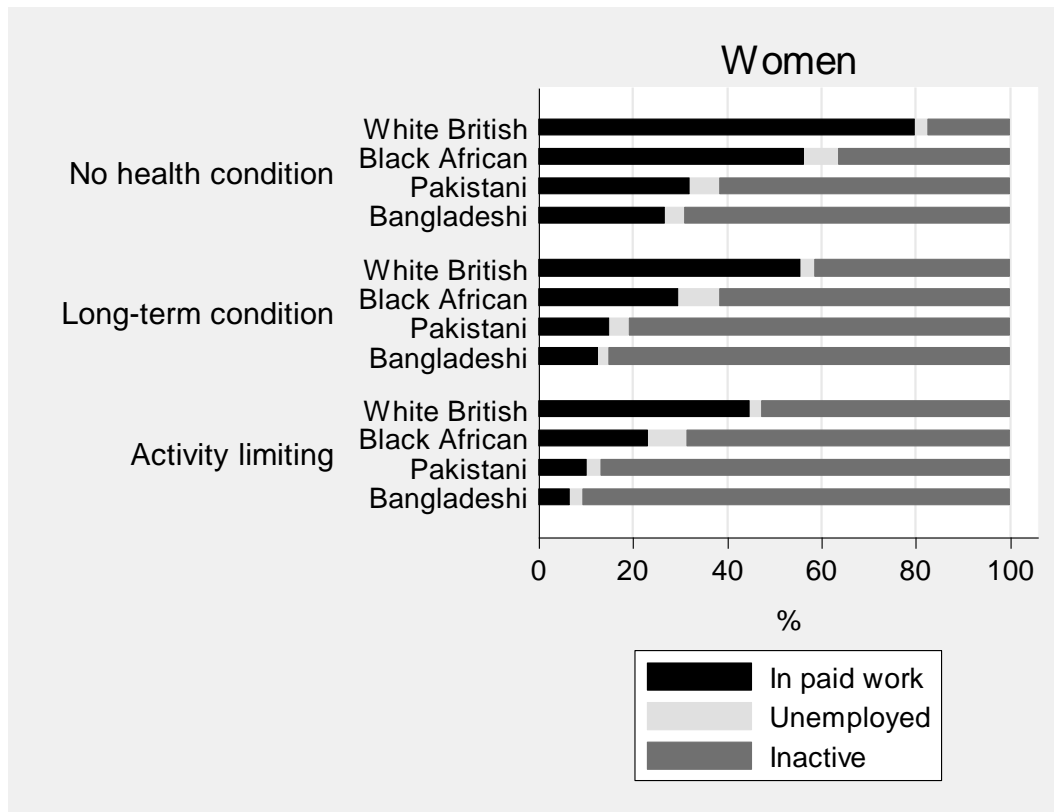
**Figure 1: Employment, unemployment and economic inactivity by ethnic group and health status: Men**



Source: Labour Force Survey, pooled quarters 2002-2005. Person weights applied.

Notes: Activity limiting refers to those who identified themselves as having a long-term illness and specified that it limited their activity

**Figure 2: Employment, unemployment and economic inactivity by ethnic group and health status: Women**



Source: Labour Force Survey, pooled quarters 2002-2005. Person weights applied.  
Notes: As for Figure 1.

Nevertheless, those who are *both* long-term sick and from a minority ethnic group are at the intersection of labour market policies to address ill health/disability and minority disadvantage. Increasingly, with the move from separate equalities bodies to a single Equalities and Human Rights Commission, launched in October 2007, the potential inter-relatedness of different forms of disadvantage is being acknowledged along with the need to tackle people's experience holistically rather than distinctly (see e.g. *Discrimination Law Review*, 2007). The intersectionality of people's experiences will tend to mean that problems or solutions are not simply cumulative (though that may be one part of the story and one approach).

In the research reported here, therefore, we set out to explore how long-term ill health was experienced across four different ethnic groups – and, specifically, its relationship to employment. While we looked at a range of dimensions of people's experience in the wider study (see Salway et al., 2007a), here we concentrate on their relationship to the labour market, to past, prospective and current employment.

## Research Methods

We combined qualitative and quantitative methods which we used together in an iterative process – suggestions from the qualitative material prompting quantitative exploration, and quantitative analysis providing us with context and issues to explore in the qualitative interviews. Given the interest in employment, we restricted our analysis to those of working age with a long-term health condition. The four ethnic groups we investigated were: Pakistani, Bangladeshi, Ghanaian (Black African in the quantitative analysis) and White English (White British in the quantitative analysis). The qualitative part of the project was largely conducted in the east London Boroughs of Hackney, Tower Hamlets and Newham, though some data collection also took place in Haringey, Lambeth and Southwark for the Ghanaians.

The quantitative analysis was based on the Quarterly Labour Force Survey (QLFS) to explore economic activity, pay and benefit receipt at the individual level and the Household Labour Force Survey (HLFS) to examine the family context of those with a long-term health condition. The QLFS is carried out each quarter, and we pooled quarters from 2002-2005. The HLFS derives from the same survey as the QLFS but groups the individuals by their households and provides some household level derived variables. It is available for the Spring and Autumn quarters of each year, and we pooled 6 quarters from 2002-2004. (For more details see Salway et al., 2007a.) We used the existing, 2001 Census categories in the data to operationalise ethnic group; and we used the question '*Do you have any health problems or disabilities that you expect will last for more than a year*' to identify long-term ill health.

In the qualitative research, we recognised that the content and boundaries of 'ethnic group' are not fixed and are 'owned' to a greater or lesser extent by particular individuals. We therefore identified potential respondents for the four 'groups' of interest and then sought to understand what ethnic identities meant to individual respondents and the implications ethnicity had (if any) for the research focus. Experience of illness was self-identified; and we stipulated illness rather than disability (which were typically understood as distinct by respondents) and that onset of the condition had occurred in adulthood. In practice this was often illustrated to potential informants through particular health conditions such as diabetes, heart conditions or depression.

The majority of the findings which follow derive from in-depth interviews carried out with those with long-term illness and their carers. However, these were preceded by an intensive phase of ‘rapid assessment’, including key informant interviews, which also informs our discussion. The in-depth interviews included history-taking methods to explore individual and household trajectories over time. Interviews were conducted in the language of respondent’s choice by members of the research team and, subject to respondent approval, were tape-recorded and transcribed. A total of 86 detailed interviews were available for analysis from the qualitative research: 57 of these were interviews with individuals with a long-term health condition, and 29 were interviews with family members. Overall, 22 interviews were completed with Bangladeshis, 20 with White English, 22 with Pakistanis and 22 with Ghanaians.

We now consider the question of family context of those with a long-term health condition, the possibility of substitution of family members following the illness of the main wage earner and the issues surround multiple caring responsibilities, and how this played out across the four ethnic groups. We also pay attention to the way family context shaped the relationship to work of those with long-term illness themselves. We then reflect on what messages these send in relation to the structure of benefits and employment support and how to maintain the most effective balance across families that is consistent with both a focus on the benefits of employment and the needs and responsibilities of family members.

### **Family, Caring and Work**

A recent article in this journal drew attention to the tensions surrounding care and work in relation to recent initiatives (Arksey, 2007). Here we focus on the demands of caring and the pressures to work within the family context, exploring the impact of ill-health across different sorts of household and focusing on the issue of multiple caring.

The availability of family support varied widely across groups, though there were similarities both in the nature of the claims that were made on other family members and the particular members who were called upon. For example, it was evident that support was frequently a source of tension across all the ethnic groups. The mismatch between family members’ perceptions of the needs of the individual with a long-term condition and his/her own wants was a common theme. The types of kin who the

respondents felt they could turn to in practice for support and care were most commonly spouses/partners and adult children, particularly daughters. The respondents also held common understandings about the desirability for certain individuals within households to be sheltered from the impact of the condition, particularly children. As one of our key informants put it, ‘I think people worry more about the children than about the person who they are caring for’”.

Nevertheless, there were differences across the ethnic groups in household composition and also in the distribution of kin outside the household, which shaped the extent to which a number of issues were of immediate concern to those with long-term health conditions or carers: taking or giving of care, perceived responsibility for protecting children from caring responsibilities, or questions of changing or adapting roles within the household.

We can see this starkly in Table 1, which illustrates the differing composition of households across the ethnic groups. Among the Black African group, almost a quarter were single person households - that is, by definition, people living on their own with a long-term condition – and thus with no potential co-resident carers or alternative workers. Among White British with a long-term health condition there were also relatively high proportions living alone. This pattern for the White British and Black Africans was reflected in our qualitative work for the White English and Ghanaians; though in the case of the White English some were nevertheless closely embedded in the neighbourhood, while many of the Ghanaians appeared relatively isolated. Table 1 also shows the very high proportion of lone parent households among Black African households. In these households, the demands on the lone parent will be substantial: not only caring for dependent children but also attending to their own health. By contrast, the high number of complex (multi-family) households among Pakistanis and Bangladeshis (22% and 26% respectively) may maximise the possibility of available carers or those able to take on alternative roles that the individual with a long-term condition can no longer manage. But around 50% of Bangladeshi and Pakistani households consisted of couples with dependent children, where the desire to protect the child(ren) from the impact of the long-term health condition can reduce partners’ willingness to take on wage earning roles. This

compared with just 25% of the White British group, among whom couples living alone were the most likely household composition (29%).

**Table 1: Household composition by ethnic group: households containing one or more people of working age with a long-term health condition (% of households).**

	White British	Pakistani	Bangladeshi	Black African
Single person	17.7	6.6	3.1	23.9
Couple without children	28.7	7.1	3.6	7.9
Couple with dependent children	25.0	46.6	50.2	21.5
Couple with non-dependent children only	11.3	6.2	4.5	1.6
Lone parents with dependent children	6.5	9.5	10.5	25.7
Lone parents with non-dependent children only	4.4	2.4	2.3	4.8
Complex (multi-family) households	6.4	21.7	25.8	14.5
Unweighted N (100%)	87356	1012	367	606

Source: HLFS 2002-2004, authors' analysis, household weights applied.

Notes: 'Complex households' include multiple family households, and couple or lone parent families where other people than (dependent and non-dependent) children are present. Same sex couples have been excluded due to small. Ethnic group is attributed to the household on the basis of the ethnicity of the household reference person.

These household level data can, of course, tell us nothing about the extent to which there are family members living close by, who provide important care and support; and most of the respondents had contact with relatives living outside the household, including kin in other cities and other countries in the case of our minority respondents, and received various forms of support from them. Childcare provided by local grandparents was particularly valued in freeing up parents to do other work. However, members of the extended family did not generally become involved in the everyday management of the health condition (such as maintaining medication regimes or dietary requirements) and its knock-on effects (such as increased household maintenance work).

The presence of alternative family members within the household may suggest the potential for switching roles when a wage-earner loses their earnings capacity. However, in practice this was not very common. The effect of an individual's health condition on the likelihood of another family member adjusting their pattern of employment was very varied and depended on a number of other factors. First the point at which such 'switching' should occur was rarely unambiguous. Among our respondents to the qualitative interviews, and consistent with other research (Burchardt, 2000; Jenkins and Rigg, 2004) we found that onset of the health condition was not typically experienced as a sudden event, but as gradual and intermittent. Many respondents had experienced multiple health conditions over several years and had experienced periods of employment and unemployment as well as periods of sickness-related leave/benefit receipt. The point of transition into economic inactivity for the person with the health condition was rarely clear-cut, particularly given the variability of the health conditions over time which was a constant theme among our respondents. In addition, those who had been primary earners could resist or resent the relinquishing of this position to another family member even in the face of difficulties gaining employment.

We also found that some family members, particularly spouses, but also adult children, had faced problems remaining in work due to the health condition of another family member. Family members were forced to take time off work in some cases because the individual needed direct care at home, but more often because s/he could not perform childcare or needed a companion for medical appointments. The latter was a particular issue for some Bangladeshi and Pakistani men whose wives lacked the necessary English language skills and confidence to negotiate the health service alone (as well as for some women whose husbands were new migrants). More generally, there was an expectation among these communities that individuals would be accompanied on medical visits that was less common among the White English and Ghanaians. Taking time off work for the health needs of another family member was very difficult and had led in some cases to leaving employment completely. On the other hand, we did find a number of cases where a partner had prioritised their earning role above potential caring responsibilities, though sometimes at the cost of the quality of the relationship.

Similarly moving from a state of non-employment to employment when a family member became ill was not often regarded as a viable option, though it did take place across all groups to a certain extent. We found that women's capacities to retain or (re)gain employment were constrained by their lower human capital, their caring responsibilities, as well as their reluctance to usurp the breadwinner role from men. This ideology was often bought into by both men and women. In cases where the health condition had become 'all-consuming' family members felt overwhelmed with day-to-day household tasks and taking up employment had not even been considered.

*"No, I am busy with children, looking after children. Now, I'm busy with my husband and children. How could I work? He's ill and so.... I have to be with him all the time"* (Bangladeshi female family member, 30-34 years)

There was some evidence that family roles were more flexible amongst the Ghanaians than in the other communities, with caring and productive roles less clearly opposed to one another, particularly for women. The high prevalence of lone parent households clearly precluded the division of types of work between men and women in many cases. Furthermore, when husbands or partners experienced health conditions, women were not always willing to sacrifice their childcare role and go out to work.

*"I've still be really wanting to stay at home and look after my children. Obviously I could have just said right he's not working I need to go and get a job and have my children looked after. But I really didn't want to.."* (White English female family member, 40-44 years)

Moreover those in caring roles were not themselves necessarily exempt from health problems, though there was some variation according to ethnic group. Examining those households with at least one working-age adult with a long-term condition, analysis of the household LFS showed that 44 per cent of Bangladeshi households in fact contained two or more people (including older people) with such a condition, compared to 39 per cent of Pakistani households, 28 per cent of White British households and 15 per cent of Black African households. Again, these ethnic differentials in part reflect the differing household structures across the groups. Even

so, the co-existence of several health conditions within one household is likely to create added strain and further restrict the ability of household members to adapt to changed circumstances. During our qualitative work, it was found that several of the individuals who we intended to interview as ‘family members’ who were experiencing living with someone with a long-term health condition in fact themselves also had such a long-term condition.

### **Family, ill-health and work**

As well as being of relevance to carers’ labour market participation, household context was often crucial in the way those with long-term health problems themselves experienced possibilities and constraints on labour market activity. Some individuals felt able to stop work because there were other sources of income to the household, and in some cases because they viewed their income as additional, rather than primary. Among White English families in our qualitative sample, since it was common for both men and women to be working, some respondents were able to ‘fall-back’ on their spouse’s earnings. In contrast, many Ghanaian respondents seemed particularly vulnerable in this respect since marital breakdown was common and families were often split between Ghana, UK and other countries. It was relatively uncommon for Bangladeshi and Pakistani women to have work experience, so that they could not easily provide a substitute for withdrawal from employment of a husband due to long-term ill-health. Furthermore, caring and household maintenance roles were often considered priorities in this situation despite the hardship caused by living on benefit income alone.

In relation to benefit support, we also found that there were differences in the extent to which respondents were supported by sickness related benefits, specifically by IB. Respondents were very aware of policy efforts to reduce numbers claiming IB, and for many this made the benefit stigmatising. In addition, difficulties with claiming, the variable nature of health conditions, self-perceptions as seeking work or as ‘not disabled’ could lead to individuals – and therefore families - not gaining support from sickness-related benefits. Our quantitative analysis indicated that rates of receipt of IB were lower for some minority groups than for majority members with similar characteristics. And while, in our qualitative data, stigma, difficulties in claiming or differences in self-perception were issues across the ethnic groups, there were

differences in intensity, with Ghanaians particularly resistant to regarding themselves as ‘sick’ or ‘inactive’, while many of the Bangladeshis appeared to face particular obstacles in having claims validated. There seemed to be a gap in this case between respondents’ perceptions of their health problems and those of professionals. Respondents expressed the view that the day-to-day variability of health conditions and the obstacles to participation presented by regular or constant pain and fatigue were not sufficiently acknowledged. And, indeed, health conditions that were variable and unpredictable in terms of symptoms and severity were particularly associated with reduced chances of a successful claim. Policy or practice interventions that utilise benefit receipt as a marker of health status will overlook those individuals with comparable levels of ill-health who are not in receipt of current sickness benefits, and we must consider the potentially detrimental implications this may have for family welfare over time.

Moreover, across the groups, while several female respondents had chosen to combine income-earning, household maintenance and child-rearing roles while fully fit, the onset of ill-health had forced them to reconsider their priorities. Fatigue was a significant factor for many of our respondents and one that reduced the number of hours in the day for active work. A number of women with long-term conditions had switched from full-time to part-time work or stopped work altogether because they felt working was compromising the quality of care they could give to their children. Importantly, this was a concern for those with older children as well as those with younger ones, with mothers stressing the importance of having time to talk to their children and help with homework. Such concerns were heightened for single parents.

*“I decided no, this work is too stressful for me, and I didn’t have time for the children. By the time I come back I’ll see I’m really tired, I can’t even help them with their homework”* (Ghanaian female with long-term condition, 45-49 years)

By contrast, one Ghanaian lone mother who had continued to work during very difficult circumstances stated that she went to work because she wanted to be a ‘normal mum’ for her children. This also shows how what it means to be a ‘normal mum’ varied with context and across the ethnic groups.

Nevertheless, across all four groups we found women who sought to emphasise their mothering (and grandmothering) roles when long-term health conditions compromised their ability to perform paid employment. And we found that non-participation in employment could present a more acceptable option for women than for men, given the availability of alternative roles within the household. However, on the other hand, part-time, flexible, often service-sector or childcare-related jobs that are more compatible with the obstacles posed by chronic illness (particularly pain, fatigue and needing time off) were perceived to be more accessible to women.

Several respondents had engaged in voluntary work as a way of gaining experience, keeping skills up-to-date, or making a slower transition back into the world of work. In some cases, this seemed to be an effective strategy, especially where the individual had prior work experience. However, it is important to note that for many individuals voluntary work did not lead to paid employment, often, they felt, because voluntary work is not considered by employers to be ‘proper’ work experience. Though, additionally, it was the fact that voluntary work could respond flexibly to the demands of health or of family that made it feasible in the first place.

## **Discussion**

The current policy emphasis on paid work as the solution to poverty and on the positive experience of work, though applicable in many instances, may need to be tempered by the recognition of the intra-household dynamics in families containing someone with chronic ill-health.

Reduced employment chances and earnings potential associated with chronic ill-health have been demonstrated in a number of studies and were supported by our own analysis of the Labour Force Survey. This is in addition to the, sometimes substantial, ‘ethnic penalties’ in employment that face those from minority ethnic groups. In this context the ‘benefits’ of work may be less salient compared to demands and responsibilities of family life, including child care responsibilities and own or partner’s health care needs. This was particularly likely to be true for our qualitative sample, given their concentration in relatively deprived areas, the relative paucity of highly rewarded skills and qualifications across the respondents, and the tendency to have employment histories in physically demanding occupations, often incompatible

with, or even contributing to, long-term ill health. While attachment to the benefits of work were present for many, particularly among those who had worked in the past, and the stresses of living on a low income could exacerbate health problems or the pressures of caring, work was often not recognised as a viable option, nor one that was necessarily in the best interests of the family, despite the economic struggles. Moreover, these issues are highly gendered: we found that the adult-worker model does not suit everybody and can make assumptions that prejudice women (Lewis, 2001)

Multiple or complex caring demands that co-exist in some households may suggest the need to reflect on the potential impact on family life of policy measures that aim to get more adults into employment. The prevalence of such households varies substantially across ethnic groups even if the issues they present do not fundamentally differ. In households with dependent children, their interests may not necessarily be best served by parents (with and without long-term health conditions) being in paid work, particularly when the economic returns to such work may not be high or the work itself stressful and demanding and not conducive to good health. Welfare reform policy may risk conflicting with other strands of policy that focus on family stability and parenting.

Recognition of the family context of long-term ill-health and caring may make appropriate intervention both to reduce those inactive through health problems and to raise minority ethnic employment rates a more vexed issue for policy, compared to regarding those with health problems in a more individualised perspective. However, the challenge of not only designating individuals as employable but also translating that employability into labour market participation will only be effectively addressed if the various concurrent constraints, not only individual characteristics but also family circumstances and employment barriers, including ethnic penalties, are adequately understood and tackled. Identifying viable avenues for intervention is further complicated by the fact that health conditions, like family circumstances and, indeed, the labour market, are not static but may change over time, reducing and increasing opportunities by turns. The availability and employability of different household members was not a steady state but fluctuated with the health of family

members, own health, the needs of children and available work options and responsiveness of employers over time.

Adopting a model of intervention that can accommodate such variation and recognise that employability and support needs may shift – and not only in one direction – is probably fundamental to realising effective support ‘for those who cannot’ work at relevant points in their working lives. In addition, attaching policy too specifically to recipients of particular benefits, risks neglecting the ways in which patterns of benefit receipt are structured by factors that go beyond simple health status, including ethnicity (see also Salway et al., 2007b).

Clearly it is important to tackle the association between long-term ill-health or disability and low income, as well as engaging positively with those who may face multiple barriers to employment, particularly sustainable or well-remunerated employment. Nevertheless there is the risk that this may come at the cost of adequate attention to the support and work continuum, and to the differing needs and priorities of household members trying, in particular, to do the best for their children.

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