findings

Long-term ill health, poverty and ethnicity

This research, led by Sarah Salway at Sheffield Hallam University, studied Pakistani, Bangladeshi, Ghanaian and white English working-age people living with long-term ill health. The study used quantitative and qualitative methods to examine why there are links between ill health and poverty, and why the consequences appear to be worse among minority ethnic groups. It found that:

- There was great variation in responses to long-term ill health. Many respondents lacked coping skills and felt little control over their situation.
- It was common for people in all four ethnic groups to conceal their ill health, and so delay or refuse help, due to strong societal pressures to be 'normal'.
- The effect of long-term ill health in reducing chances of employment was similar across ethnic groups. However, older Bangladeshis and Pakistanis appeared to be more accepting than white English or Ghanaians of their limited prospects of paid work. Younger people and men often found it harder than older people and women to accept alternatives to paid work. Commitment to employment was positive for some, but for others it conflicted with their health needs or undermined other important roles (such as child-rearing).
- Individuals with long-term conditions required substantial flexibility in employment, due to pain, fatigue, unpredictable symptoms and health appointments; this could conflict with employers' needs for reliability.
- Overall, carers were more likely than those with long-term ill health to miss out on social participation. Low income (often a consequence of long-term ill health) affected social contact, and ill health could make contact less enjoyable and supportive. Ghanaian women were most at risk of isolation, while Pakistani and Bangladeshi women with long-term health conditions often found social contact stressful.
- Financial hardship was common, particularly where 'sickness' benefits were not received. A reluctance to be identified as 'disabled' or 'incapacitated' made some unwilling to claim. However, the system itself was a barrier, being seen as unfair, stressful and complicated. Minority ethnic individuals were less likely than white people to receive 'sickness' benefits.
- Effective professional support was generally lacking. Minority ethnic respondents seemed particularly disadvantaged; while limited English language competence was a problem for some, there were general feelings of exclusion from mainstream society and services.

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Background

This study explored the relationship between long-term health conditions and poverty across a diverse population. Poverty was broadly conceived and covered three domains: financial hardship, lack of participation in employment and limited social participation. Combining investigation of large-scale nationally representative surveys with in-depth qualitative work in a deprived area of London, the study explored people's experiences of long-term ill health and how they managed this, and its relationship with poverty and identity. The study included individuals with a range of health conditions, and concentrated on working-age individuals who had acquired their condition during adult life and who identified themselves as belonging to one of four ethnic groups: Pakistani, Ghanaian, Bangladeshi and white English. The research highlighted respondents' various understandings of and reactions to living with long-term ill health as well as looking at the impact of ill health on the three areas of poverty. It explored both constraints and coping strategies and identified points of similarity and difference across the four ethnic groups.

Consistent with previous research, the study found that:

- Health problems were often clustered, with individuals suffering from multiple conditions.
- Ill health was closely related to labour market outcomes, in particular lower participation in paid employment, but also low pay.
- Those with long-term health conditions experienced a range of barriers to employment, despite having a strong work ethic.
- Claiming disability benefits was perceived as a struggle and stressful, particularly among those with mental health problems.
- Difficulties making ends meet had a deleterious effect on health and on household well-being.
- Attitudes to ill health, and the way it was experienced, varied with ethnicity, as well as age and gender.

The study also revealed a number of less well-recognised findings.

The consequences of health problems

Attitudes to ill health

While some respondents showed remarkable buoyancy and enthusiasm for life, others were struggling and showed signs of serious emotional upset. Strong pressures (from self, family and community) to be as 'normal' as possible sometimes conflicted with the need to mentally adjust to the condition. Across all four ethnic groups, concealment of ill health and impairment was common.

However, the minority ethnic respondents were more likely to explain their actions in terms of expected behaviour for their community, thereby presenting concealment as an essential characteristic of 'our people' or 'our culture'. Among the Pakistani and Bangladeshi respondents, hiding ill health was particularly associated with the feminine ideal of suffering in silence, whereas among Ghanaians it was strongly identified as typical for both men and women. Downplaying ill health could have negative implications, such as delays in seeking healthcare or refusing help. It also encouraged individuals to cling onto prior roles and behaviours, even where these conflicted with health-related needs.

Respondents varied in the extent to which they accepted their health conditions and made adjustments to take account of them. Cultural context, socio-economic position and family circumstances all affected whether pre-existing social roles could be given up without seriously undermining self-identity, and whether suitable alternatives existed. For example, older Bangladeshi and Pakistani men appeared to find it easier to regard long-term health conditions and associated inactivity as a natural stage in life than their white English or Ghanaian counterparts. In general, younger individuals and men found it more difficult than older individuals and women to accept roles other than paid work.

Attitudes and access to support

How people think of themselves and their health condition has important implications for how they respond to the challenge of living with ongoing ill health, and for the support they seek to access. There was often a tension between resisting ill health and getting appropriate support. This tension was particularly evident in relation to welfare benefit access. Quantitative data revealed that minority ethnic groups were less likely to receive sickness and disability benefits than white English individuals with similar ill health. Qualitative data suggested that a reluctance to be identified as 'disabled' and negative attitudes towards 'welfare' discouraged uptake, but these could be overcome if the financial imperative was severe enough.

More important than attitudes was a lack of understanding of eligibility conditions and the difficulties of the application procedure itself. Individuals across all four groups saw claiming benefits as complex and stressful. Moreover, rejected claims could induce a sense of being devalued. Making a successful claim appeared to be particularly hard for those with mental health problems and the stress involved could aggravate conditions.

Financial hardship could also exacerbate health problems. Among our sample, many had suffered mental health conditions after their diagnosis with a physical condition. This often appeared to relate not only to the challenge of managing and adapting to the health condition itself, but also to the financial stresses associated with it. Even though very few claims for certain benefits, such as Disability Living Allowance, succeed without informed assistance, few of our respondents had received professional help in making applications.

Social networks
Social networks tended to be ethnically-based (though this was less explicit for the white English sample) and this could both aid and inhibit the extent to which they were productive sources of information and support. In the sample, Pakistani networks were particularly effective for information exchange, while the Ghanaian networks tended not to provide information on management of ill health and social security benefits – topics that were highly sensitive. Despite the apparent proliferation of community and health-related groups and resources available to Bangladeshis, their access to relevant and accurate information seemed limited.

Networks were also opportunities for social interaction. Very different patterns of social participation were found across the ethnic groups. Bangladeshis and Pakistanis had high levels of reciprocal home-based contact with wider kin, while patterns of social activity beyond the home were more restricted, particularly for women. 'Going out' was more prevalent among the white English, with the pub still being a centre of social activity for many. However, possibilities for going out were heavily constrained by finances. Among the Ghanaians, membership of organisations and churches was common, and attendance at meetings and functions was important as well as family-based socialising. Ill health could affect participation in different ways. For the Ghanaians, physically accessing organised activities some distance away could be difficult and Ghanaian women were at high risk of social isolation.

By contrast, while Bangladeshi and Pakistani respondents often had local family networks which facilitated ongoing contact, ill health could change the meaning of that contact. Obligations to entertain and feed visitors could become a source of stress rather than enjoyment for those with painful or tiring conditions or demanding caring responsibilities. Women in these groups were particularly likely to report social networks as stressful rather than supportive.

Ill health and employment
Many respondents, both those with long-term conditions and carers/family members, wanted to work. Having a job was regarded as a positive end in itself, but substantial barriers were experienced. Many could no longer physically do jobs they had done in the past. In addition, the fatigue and pain that accompanied many long-term conditions, as well as the unpredictability of symptoms, meant that only highly flexible employment was possible. Individuals with ill health – and those carers who needed to accompany them – could require substantial time off to attend regular medical appointments. Some respondents felt let down by employers in relation to their needs for flexibility; others regarded themselves as a liability from an employer's perspective. While some individuals effectively managed the limitations imposed by their ill health and continued in paid work – for example by lying down at lunchtime – for many it was hard to conceive of effective strategies. There is clearly a tension between employers' needs for reliability and the flexibility needed by those with a long-term health condition. It was particularly frustrating for those individuals who were not sick enough to qualify for Incapacity Benefit but also not well enough for employment.

The qualitative work suggested some differences in attitudes towards labour market participation across the ethnic groups, particularly by age and gender. Nevertheless, the quantitative analyses indicated that long-term ill health has a similar negative effect on the employment chances of all four ethnic groups. Although reduced chances of employment are similar across groups, individuals' experiences and the extent to which they might need additional support to come to terms with not working are likely to differ.

Impact on parents
Those with long-term ill health and their carers/family members often had other roles besides that of (potential) employee, particularly as parents. Maintaining such roles alongside the demands of paid employment was often very difficult. However, respondents were reluctant to abandon such roles and often prioritised them over working, even in the face of serious financial pressures. The extent to which the dual needs of both long-term ill health and dependent children co-exist in households varied greatly across ethnic groups, being most common among Bangladeshi and Pakistani families. However, there were large numbers of single parents among the Ghanaian sample, presenting particular difficulties for managing ill health, productive work and child-rearing simultaneously. Furthermore, though remaining in employment was a positive thing for some, in other cases it clearly led to frustration and unhappiness and was a

reflection of maladjustment to the reduced capacity and increased needs accompanying ill health.

Policy implications

Supporting employment for those with long-term ill health requires recognition of the need for flexibility that such conditions impose. Balancing these needs with employers' (particularly small employers') requirements for a reliable workforce requires strategic intervention to encourage and enable employers to recruit and retain such workers. Retention in existing work will be crucial for some, but will only be sustainable where adequate allowance is made for the individual's changed needs and capabilities. For others, a period outside employment may be more appropriate to allow time for mental adjustment and recovery, though this is likely to require professional support for an eventual successful return to work.

The jobs accessible to those with a long-term condition are often not of a type that they can carry out. Jobs that may be more compatible with ill health often require higher qualifications and skills. Promoting skills development, for those in employment and for those who are economically inactive, therefore has an important role to play. For some, however, it must be recognised that engaging in paid work may not be in the best interests of the individual or household. Developing appropriate financial support for those with multiple caring roles and those whose ill health precludes sustained employment could be a beneficial policy in government.

High levels of financial hardship result from lack of earnings and also lack of access to relevant benefits. Given that financial hardship can exacerbate existing health conditions and lead to stress-related ones, the costs of not delivering benefits must be acknowledged. Addressing barriers to take-up among eligible non-claimants has an important role in balancing out current policy, which restricts entitlement.

Individuals across all ethnic groups require greater support in coping with the daily management of their health conditions and the knock-on implications for benefit take-up, access to employment and social participation. Widespread reluctance to engage in ill health support groups indicates the need for varied modes of support delivery. Though local ethnic networks can be productive, the bigger picture suggests that minority ethnic respondents are particularly lacking in support. Strengthening ethnicity-specific community organisations is a potentially important route to improving access to resources including welfare benefits. However, statutory providers also have a duty to address the feelings of exclusion from mainstream society and services that are a more general barrier to support for minority ethnic individuals.

About the project

The study was carried out between February 2005 and July 2006, by researchers at the University of Sheffield, Sheffield Hallam University, University of Essex, the London School of Hygiene & Tropical Medicine and Social Action for Health. It was based upon secondary analysis of the Labour Force Survey 2001-2005; the Citizenship Survey 2001; published Tables from the 2001 Census; and an extended period of fieldwork in the East End of London between April 2004 and February 2006 which had three phases: rapid assessment, 86 in-depth interviews and community feedback.

For further information

The full report, **Long-term ill health, poverty and ethnicity**, by Sarah Salway, Lucinda Platt, Punita Chowbey, Kaveri Harriss and Elizabeth Bayliss, is published for the Foundation by The Policy Press (ISBN 978 1 86134 993 4, price £15.95).

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