

Better
Health
Briefing

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**Long-term
ill health,
poverty and
ethnicity**

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A Race Equality Foundation
Briefing Paper

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Key messages

- 1 The social and economic consequences of long-term ill health are greatest for deprived groups and certain minority ethnic groups. These groups face the highest rates of long-term ill health and worklessness and are also most marginalised from support services
- 2 Coping with and managing a long-term health condition is strongly affected by the family and household context. But health and welfare services often focus only on the individual, which can be problematic for patients and their family members
- 3 Social support is key in helping people to come to terms with and manage a long-term health condition. However, many long-term sick people find it hard to maintain their usual social contact and face difficulties in participating in group-based interventions
- 4 Although many long-term sick people do want to work, policies and services aimed at encouraging people into employment can be problematic as work can impact negatively on their health. Caring obligations create conflicting priorities within households
- 5 The take-up of sickness-related benefits among eligible people is low, particularly for minority ethnic groups. For many people, the benefits system is experienced as complex, unpredictable and stressful. Wider access to specialist support is required.

Introduction

Long-term ill health is defined by the World Health Organization (2002) as health problems that require ongoing management over a period of years or decades. Long-term ill health is a problem that afflicts a third of working-age adults in England and Wales, particularly people who experience deprivation and people from certain minority ethnic groups. Diseases of the heart and circulatory system, diabetes, arthritis, respiratory disease and mental ill health are most common (ONS, 2001). Moreover, physical and mental health are closely interlinked. People with mental ill health are disproportionately likely to develop physical health conditions, and experience major inequities in accessing health care (DRC, 2006). Long-term ill health is associated with multiple forms of social disadvantage, and is a leading cause of impoverishment in the UK at present (Jenkins and Rigg, 2001). The response to these issues in health and welfare policy has become increasingly multisectoral. Health policy towards long-term condition management promotes self-care, case management, disease management and healthy lifestyles, with the imperative to improve quality of life and reduce the burden of caring for long-term conditions to the National Health Service (the care transition) (DH, 2008). Welfare policy views employment as the main route out

of poverty, and greater attention has been paid to the economic inactivity of individuals with long-term conditions (DWP, 2006). In recognition of the complex links between long-term ill health and disadvantage, health and welfare policy increasingly expects practitioners to be able to bridge expertise in both arenas and build more fluid connections between services. This raises major challenges for infrastructure and training, and creates potential tensions and ambiguities in the roles of many health and welfare practitioners, such as GPs, nurses, health visitors, self-management tutors, jobcentre staff (including specialist disability advisers) and the voluntary sector.

Care transition and welfare-to-work policies have important implications for the well-being of the people who are most marginalised, and support services seem to be less accessible and responsive to the needs of long-term sick people from minority ethnic groups (Salway *et al.*, 2007a). Equity is a particularly important issue in care transition and welfare-to-work policies, as these have the potential to marginalise further the people who are least able to help themselves (Fothergill and Wilson, 2007; Taylor and Bury, 2007). This paper reviews why the consequences of long-term ill health are more severe among minority ethnic groups, and the role that services can play in mitigating the disadvantage entailed by ill health. It suggests how practice can be better adapted to meet the diverse needs of service users.

Differing levels of ill health and heightened marginalisation require recognition in policy and practice

Minority ethnic groups as a whole are more likely to report long-term ill health than the white British ethnic majority. The Health Survey for England in 1999 and 2004 showed that the ethnic differentials in health have persisted over the last decade, and, for women, have even deteriorated (Sproston and Mindell, 2006). The links between ill health and poverty are also particularly extreme for minority ethnic groups. Long-term sick minority ethnic people have lower economic activity rates than their white British counterparts, and are more likely to be unemployed (Simpson *et al.*, 2006). Racial discrimination has consistently been an important factor causing ill health and excluding minority ethnic groups from employment and welfare resources (Karlsen, 2007).

Survey data suggests higher than average use of primary care by certain minority ethnic groups, although not relative to need; lower than average use of secondary care; and ethnic differences in the quality of experience (Aspinall and Jacobson, 2004). Ethnic differences in the treatment and management of severe mental health conditions are extreme, although this appears not to be the case for community mental health services (Fearon *et al.*, 2006; Raleigh *et al.*, 2007). However, ethnic inequalities in health have not received specific attention in health inequalities policies or welfare policies. Although area-based programmes focused on deprived areas indirectly concentrate funding and effort towards minority ethnic groups, they may fail to engage marginalised groups. It is therefore essential that policy makers and health and welfare managers improve the coverage of ethnic profiling in order to monitor service use across ethnic

Resources 1

NHS Library

www.library.nhs.uk/healthmanagement/ViewResource.aspx?resID=32021&tabID=290

This website provides an up-to-date compilation of the Department of Health's key policy documents concerning the management of long-term ill health.

DIPEX

www.dipex.org/DesktopDefault.aspx

DIPEX is a website from which users can watch, listen to and read the narratives of patients living with a number of long-term health conditions. It includes patients and carers from minority ethnic groups. A specific project compiling narratives of mental ill health in black and minority ethnic groups will be on the website from March 2008.

The King's Fund

www.kingsfund.org.uk/publications/kings_fund_publications/index.html

The King's Fund carries out important policy analysis and research in the field of health and social work, particularly in London. It has a strong programme of work on the health of minority ethnic groups, long-term conditions and disability.

Joseph Rowntree Foundation

www.jrf.org.uk/bookshop/

The Joseph Rowntree Foundation is a social policy research and development organisation. It is a major sponsor of research on the welfare of minority ethnic groups in the UK. The website contains a number of qualitative research studies presenting the experiences and views of long-term sick and disabled people from minority ethnic groups.

groups, identify disparities and suggest where resources should be allocated to improve access. It is also key that front-line staff should be trained to work with diverse service users in a culturally competent manner, but without falling back on stereotyping assumptions (Atkin and Chatoo, 2007; Kai *et al.*, 2007).

2 The family and household context strongly affects the consequences of ill health

Research has shown that individual responses to long-term ill health are variable and contextual. The family and household are particularly strong influences over how people come to terms with, cope with and manage a long-term health condition. In some people's minds, other household problems may be more significant than their illness. In minority ethnic groups, these may include complications related to migration, immigration issues and the separation of family members in different countries (Higginbottom, 2006; Salway *et al.*, 2007a). The cooperation of family members is essential for long-term sick people to be able to adhere to medical advice concerning health management, diet and lifestyle (Mir and Din, 2003).

Household composition affects whether people have access to live-in informal care from others, or whether they have to juggle their own health needs alongside caring for other people. Long-term sick people living in single-person households may be in particular need of support, while lone parent and complex, multigenerational households may bring onerous caring responsibilities and competing priorities for care. For some people, paid work may be impossible or valued less highly than maintaining domestic responsibilities, which can actually be just as important in protecting the welfare of the family as a whole (Lewis, 2001). Importantly, household structures vary between ethnic groups (Modood and Berthoud, 1997), as does the salience of cultural expectations about the provision of family care (Platt *et al.*, 2008).

In familial cultures the ideals of individual autonomy and independence may be less important than interdependence, and it may be easier for people to be recognised as sick and allowed to remain inactive (Hussain *et al.*, 2002). However, it is equally important for practitioners to recognise the links between the negotiation of dependency and care, and oppressive power relations within families. It is well established that informal carers in minority ethnic groups are often over-burdened and under-supported in the same way as carers from the ethnic majority (Katbamna *et al.*, 2004). The Expert Patient Programme, the self-management programme supported by the NHS, contains a component to support family carers in coping with the challenges they face. The Race for Health programme in Bradford and Airedale Primary Care Trust (PCT) has examples of culturally competent good practice in which South Asian family members have been involved in diabetes health promotion to encourage the family-wide adoption of dietary change.

Tensions over acknowledging ill health restrict social participation and hinder coping

3

Many long-term sick people face difficulties in social participation, and informal networks are not always able to provide long-standing support. Research suggests that the relative importance of the numerous barriers to social participation varies between ethnic groups (Salway *et al.*, 2007a). Many long-term sick people are ambivalent about acknowledging and revealing ill health due to the desire to preserve normality in their social relationships. People with mental ill health and conditions such as HIV/AIDS have strong perceptions and fears of stigma. The desire for concealment is particularly heightened when people are living in close-knit communities and are dependent on reciprocal within-community ties, as in certain minority ethnic groups (Katbamna *et al.*, 2000). At the same time, despite their greater frailty, people from minority ethnic groups tend to have a more positive view of ageing than their white counterparts (Moriarty and Butt, 2004).

Social support is extremely important in helping people to come to terms with and successfully manage a long-term health condition. However, the current policy focus on self-management, through participation in group-based interventions such as the Expert Patient Programme, may exclude individuals who are unwilling to identify themselves publicly as sick. For people with mental ill health, the prospect of joining a support group may be threatening to individual identities. There is therefore a need for diverse modes of support for people living with long-term health conditions. Attendance at self-management groups and support groups organised around specific illnesses appears to be biased towards white middle-class people. People experiencing deprivation and people from minority ethnic groups have been under-represented in the Expert Patient Programme to date (Kennedy *et al.*, 2007). However, there are some good practice examples, which broadly highlight the importance of recruiting lay tutors from minority ethnic groups. The Expert Patient Programme has been delivered in eight different languages. Coventry PCT is currently evaluating a self-management programme for Punjabi Sikhs with arthritis, and there have been positive results for diabetes self-management with Bangladeshi people in Tower Hamlets (see Griffiths *et al.*, 2005).

The capacities and attitudes of long-term sick people towards work are varied

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Welfare-to-work programmes appear to have had some success in supporting long-term sick people into employment (Bambra *et al.*, 2005), although supporting people with severe mental ill health is more challenging (Burns *et al.*, 2007). Targets for increased numbers of long-term sick people in employment encourage jobcentre staff to focus on getting clients into any employment rather than identifying *appropriate* employment and providing training, which have been shown to be more important for job retention in the longer term (Lindsay *et al.*, 2007). Unpredictable and episodic illness, pain and fatigue, and the burden

Resources 2

Race Action Net

www.raceactionnet.co.uk/

This website has been created as a means for organisations to share good practice in tackling racist harassment.

NHS Specialist Library on Ethnicity and Health

www.library.nhs.uk/ethnicity/

The NHS Specialist Library is a collection of the best available evidence relevant to providing health care to minority ethnic groups in the UK. The evidence base is organised into diseases and conditions, service delivery, cultural competence, and management and policy statistics to facilitate access.

Race for Health

www.raceforhealth.org/

The Race for Health Programme is funded by the Department of Health to support a network of fifteen PCTs in developing and collating best practice concerning racial equality in the delivery of health care. The projects are evaluated by peer review.

Mosaic

www.mosaic.nhs.uk/

The Mosaic project at the Department of Health aims to provide up-to-date information and advice on how to pursue racial equality through commissioning and procurement in health care. It is aimed at purchasing staff, suppliers and policy makers.

of medical appointments, are aspects of long-term ill health that are frequently overlooked by employment support workers. Practitioners need to consider the benefits of work alongside its potentially negative health impacts, as juggling work alongside complex health management needs and caring responsibilities may have a detrimental impact on people's overall well-being (Glaser *et al.*, 2005). Job-search support needs to be tailored to individual needs, although equally, as mentioned previously, it is important for practitioners not to fall back on stereotyping assumptions.

Volunteering may serve as a stepping stone to employment, although for some people it must be recognised as an end in itself. Policy makers and practitioners also need to appreciate that the capacity of long-term sick people to participate in employment is limited by the job opportunities presented by the local labour market (Fothergill and Wilson, 2007). Low pay deters many long-term sick people in deprived areas from seeking employment (Katungi *et al.*, 2006). There are also real tensions between employers' needs for a reliable workforce and the unpredictable and disruptive nature of long-term ill health, and the capacity — and incentives — for employers to offer flexible opportunities to long-term sick people require practical and legislative support. The combination of obstacles to employment resulting from ill health, low skills and racism can result in particularly low chances of employment for minority ethnic groups, and low pay for those who are in work (Salway *et al.*, 2007a). There is no evidence on which to evaluate whether welfare-to-work initiatives have reached equally across ethnic groups. Diverse modes of outreach are needed to ensure that employment support is accessible to marginalised groups. Pathways to Work, a Jobcentre Plus-led programme of work-focused activities for people claiming Incapacity Benefit, has piloted a scheme placing jobcentre advisers in GP surgeries to improve access to long-term sick people.

5 Low take-up of sickness-related benefits

Sickness-related benefits are an essential, if not necessarily fully adequate, contribution towards maintaining standards of living. However, the take-up of benefits among eligible people is low. Further, levels of work-restricting ill health among claimants of unemployment-related benefits are high, implying that significant numbers of people do not take up ill health-related benefits that could improve their standard of living when they develop a health condition (Bacon, 2002). Importantly, the receipt of sickness-related benefits seems to be particularly low for minority ethnic groups (Salway *et al.*, 2007b). Access to benefits among long-term sick people appears to be limited by a lack of knowledge, which may be compounded by English language difficulties in minority ethnic groups as well as marginalisation from welfare services due to actual or perceived racial discrimination (Barnard and Pettigrew, 2003).

Aversion to benefits dependency needs to be countered by an entitlement-based approach, and the culture of stigmatising sickness claimants as undeserving needs to be challenged. The assessment procedures for benefits are frequently experienced as complex, unpredictable and stressful, despite

evidence that levels of fraud are low (Hedges and Sykes, 2001). Responding to criticisms following the consultation for the Welfare Reform Green Paper, the Personal Capacities Assessment has recently been revised to take greater account of the needs of people with mental ill health. Although entitlement criteria are complex, it is important that a wide range of practitioners (GPs, nurses, health visitors, social workers, housing officers) should be able to provide advice about and support for claiming relevant benefits.

Misunderstandings need to be combated, and those practitioners who are unable to provide support need to be able to refer on. It is well established that few claims for benefits are successful in the absence of professional assistance. Specialist support needs to be expanded. In England, however, the number of GP surgeries offering benefits advice has declined since 2005 (Elliott, 2007). There is some evidence that minority ethnic groups are at a disadvantage in accessing specialist support (Salway *et al.*, 2007a), and there is a need to diversify modes of outreach to ensure that benefits support is accessible to more marginalised groups.

Conclusion

In the past decade increasing attention has been turned to the burden of long-term ill health and the combination of factors causing poverty and disadvantage among the long-term sick, including the high levels of long-term ill health in certain minority ethnic groups. Equally, however, shifts towards care transition and welfare-to-work policies have had negative implications for the well-being of people who are most disadvantaged and least able to help themselves. Qualitative research suggests that there is a disjunction between policy statements, which suggest that such initiatives provide support and encouragement to long-term sick people, and experiences on the ground, which suggest that there is a danger that such policies stigmatise long-term sick people, further disadvantage the most vulnerable, and fail to consider the knock-on effects for other family members. All too frequently, the patchy completion of ethnic monitoring prevents the evaluation of ethnic disparities in the uptake and outcomes of initiatives. However the existing evidence suggests that many programmes are failing to successfully reach minority ethnic groups. There is a need to diversify outreach to better include minority ethnic groups. The recruitment of minority ethnic staff and provision of support in community languages will be important in this endeavour, although they are not catch-all solutions. Training in cultural competence is also needed, although care is needed to ensure that the awareness of cultural difference does not translate into stereotyping responses.

Resources 3

Welfare Reform

www.dwp.gov.uk/welfarereform/

The Welfare Reform programme from the Department for Work and Pensions will be rolled out nationwide during 2008. The website gives an overview of the employment support that will be provided to long-term sick people and changes in benefits rulings that will affect claimants following the 2006 Welfare Reform Green Paper.

Social Market Foundation

www.smf.co.uk/assets/files/publications/Disability,%20skills%20and%20work.pdf

The Social Market Foundation study available on this website was sponsored by the Disability Rights Commission. It calculates that improving the skills of the 6.8 million working-age disabled people could give Britain a £35 billion boost over the next three decades.

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We welcome feedback on this paper and on all aspects of our work. Please email briefings@racefound.org.uk

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