

Editorial

One small cheer

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There is progress. Throughout the UK, health and life expectancy have increased even amongst the more disadvantaged sections of society (Department of Health, 2008a). Employment rates, even for those with health problems, are increasing (Department of Health, 2008b). At least the third report of the Health Inequalities Unit at the Department of Health on Progress in the Programme for Action (Department of Health, 2003) has found enough progress to report on, and even some cause for optimism (Department of Health, 2008c), and does not entirely seem to fudge the issue. However, while this information is very encouraging, there is still much to be done. Improvements have not been evenly spread, and so progress is much slower amongst the poorest when compared to those better off. For those of us concerned about health, social care and diversity, this is hardly news but it is nonetheless welcome; we are no longer a small band of voices in the dark.

The problem is that the causes of health inequalities are not simple. Rather, they are the product of a complexity of interrelated issues so that 'action on a broad front and across a range of health determinants is necessary to halt and narrow the health inequalities gap' (Department of Health, 2008a, p.14). Thus we can draw some comfort from the UK government's insistence that there is a comprehensive programme for change, and that many intervention projects are in operation or planned, as noted by the then Minister for Immigration in his editorial earlier this year (Lewis, 2008), and we welcome the fact that evaluations and progress reports from many health and social care bodies are beginning to include explicit recognition of and reference to these new targets and the related challenges. At last government is listening and proposing a whole series of initiatives linked to five key areas: babies, young children and parents, work, health and well-being, promoting equality, developing mental health services and coordinating activities. Work is a particularly important area. It is estimated that, in the UK, 175 million days in 2006 were lost through

sickness/absence, some of which could have been avoided by changes in either lifestyle or working conditions. Every year, over 600 000 people move on to incapacity benefit; over half of these do so directly from work or following sickness/absence from work (Department of Health, 2008b). The estimated cost of sickness/absence and unemployment associated with health problems among people of working age is £100 billion, more than the entire gross domestic product of some less wealthy nations (Department of Health, 2008b, p.16). Work matters because it provides one of the best means of avoiding and escaping health inequalities. Those without work are more likely to be living in poverty and, consequently, have fewer resources to manage or improve their health. Thus, while it may be tempting to dismiss the figures we have presented here as a problem only for the rich, the relationship between work and health inequalities cannot be ignored in any society, especially at a time when global economic recession is likely to affect the lives of many millions of people. This recession will affect everyone's health, but that of the poorest and most disadvantaged will suffer more acutely. We can only hope that the recession will not be used as an excuse to avoid health inequalities. We hope that we shall see a genuine step change, a move away from sticking-plaster patches of short-term projects towards real and sustained improvements, but we still look in vain for confirmation that there has been substantial and sustained, irreversible change.

Professor Sir Graeme Catto, President of the General Medical Council (GMC), and our first guest editorial writer in this issue, draws attention to some crucial aspects of structural determinants – that is, the competences and attitudes of healthcare professionals. The GMC, through its series of statements and booklets, has played a key role in setting the agenda for training, regulation and management of the medical workforce and its attitudes and behaviour towards those who are 'different' in any way. In particular, perhaps, we might highlight the recently published

guidance on personal beliefs (GMC, 2008), ranging from dealing with Jehovah's Witnesses' beliefs on transfusion, through circumcision to dress codes. There is also a very useful set of 12 'Valuing Diversity Resource Guides' (www.gmc-uk.org/publications/valuing_diversity/index.asp) produced by the GMC. Sir Graeme neatly highlights the balance between the tolerance that doctors must extend to their patients, and the equity and consistency that they should expect in their training and disciplinary procedures. As the GMC, along with many other elements of the NHS, has been late to record data on ethnicity (and other aspects of diversity), the roles of research and a properly constituted Single Equality Scheme are crucial in moving forward, whether on concerns about equality for migrants, ethnic minority groups, communication-impaired and disabled people or the needs of LGBT communities.

In a second guest editorial, we are extremely pleased to welcome a contribution from Emeritus Professor Elizabeth Anionwu, who has followed a distinguished career and played a very significant role in the development of an NHS sensitive to multicultural, multi-ethnic needs. Her focus on sickle cell disease reminds us that although 'common diseases occur commonly' (and we have had occasion in the past to argue that the common needs of black and minority ethnic (BME) populations have been neglected), to leave out their specific needs while continuing to privilege the specific needs of the white majority is not equitable. And, as our first research paper also shows, this is an international issue. Anionwu's editorial shows how long it can take to change things and, although she is too modest to say this, how much such change depends on the energy and passion of individuals such as herself. We thank her for that, and for giving us further closely argued and well-evidenced ammunition to call for more rapid improvement in provision, training and monitoring of services as well as the research and necessary resources.

The papers in this issue continue our focus on empowerment and the potential that exists within communities to make a difference for themselves. Thus we consider the role of technology and training, and the recognition that community members, and those living with a disease condition, are the experts on themselves. However, as we are sure Professor Catto would agree, healthcare professionals are still often at a loss as to how to release or support those energies. In this context we are pleased to present a paper spanning three continents: Dennis-Antwi (Ghana), Dyson (UK) and Ohene-Frempong (University of Pennsylvania) explore the scourge of sickle cell disease (SCD), which affects up to one in 50 of all children born in Africa, and in that continent may lead to 95% mortality before the age of 5 years. This is, as Anionwu and others have shown, one of the best researched of all genetic

conditions. Even accepting the resource constraints that bedevil Africa, an intermediate strategy does exist to ameliorate this threat, and it can be seen to fall clearly within the ambit of the much vaunted and under-resourced Millenium Development Goals which have been given such a high profile in the UK by the prime minister's personal commitment and leadership. The authors set out to see what has been found in research into healthcare and support for families with SCD, and how far this can be translated into African contexts.

Evidently, and realistically, the high-tech solutions available in the west are too expensive for emergent economies such as that of Ghana. This does not mean that nothing can be done. An estimated incidence of nearly half a million affected births per year really does represent an epidemic. So why is nothing apparently being done? Communicable diseases, especially malaria and HIV/AIDS, which can transfer to other populations, seem to get all the attention. That said, the paper does document the potential for success when resources and energetic advocates can be found. Ghana has made great strides in attacking the issue of SCD screening. Whilst some aspects of an SCD programme may be expensive when implemented in the west, this paper demonstrates that they can be greatly reduced within the context of a developing country by selecting elements of a comprehensive strategy. One of the most significant and cheapest methods might be investment in some basic training for both patients and clinicians, a topic discussed by Alam and Singleton later in this issue. While still cripplingly expensive in an African economy, the costs would hardly trouble the balance sheets of many large capitalist enterprises, at least before the present self-inflicted credit crunch caused by speculative investments, were any to adopt this as their chosen campaign.

In our next paper the Flynns highlight the fact that communities often seen as 'hard to reach' and of rural or otherwise troubled backgrounds may actually be in advance of the settled majority in their access to and use of new-generation technologies. While there is no reliable evidence on the levels of access to the Internet available to different ethnic and diasporic groups, their paper is highly suggestive, and we know, from personal contacts, how many people of South Asian origin are well informed and connected to the subcontinent through satellite TV as well as the Internet. The Flynns demonstrate how Somalis in Manchester, who are clearly in need of health service support but appear to mistrust the existing NHS services, or at the very least to have had bad experiences in their dealings with primary care, appear to trust electronic sources of information and insist that they would like these to be certified or validated by the NHS, a suggestion that might be of benefit to everyone. Thus, they argue, the use of pathways like NHS Direct Online and the NHS

(electronic) Library can be the basis for re-engagement and health improvement. Despite appearances, and maybe some media stereotypes, a high proportion of Somali refugees are well educated and from middle-class backgrounds. Nearly all have, and rely on, children of the Internet generation to help them source appropriate information. There are also significant community centres where Internet facilities are available, with the support of bilingual community workers.

However, all those questioned insisted that they would only feel comfortable with NHS-validated information, unlike the many native British patients who appear to use anything and everything that they can find with basic search engines. It was, therefore, useful to learn recently that the Australian healthcare system has been conscientiously accumulating translated medicines and other health-related information in the many languages spoken by settlers (see for example the website of Multicultural Mental Health Australia: www.mmha.org.au – and also the Australian National Prescribing Service website: www.nps.org.au). Altogether, the Flynn's paper raises a number of questions about how people consult and share information, while suggesting that eHealth developments are more of an opportunity than a threat to health-deprived communities.

In our third paper, Alam and his colleagues at Warwick draw attention to the needs of another deprived community, people of Bangladeshi origin. Their research highlights the clinical need for, and the lack of properly evaluated, educational initiatives to support self-management of diabetes, one of the world's most common conditions. It also uncovers the specific problems of a population that is not only largely non-literate in English, which is not an uncommon thing in migrant populations, but also one that speaks a language/dialect that has no accepted written form. It is clear that, as in the case of SCD, despite the passage of time since this was first highlighted, either nothing has been done, or if it has been done, it has not been reported and learned from. Where projects have been undertaken, they have been under-evaluated, without the degree of attention to outcomes and recording that one might expect in an evidence-based, scientific service. Alam and his colleagues raise challenging questions about the transferability of knowledge, and highlight that the Sylheti people of Bangladeshi origin are not the only non-literate or non-written cultural population of concern.

As emphasised by both our guest editorials and indeed the other papers in this issue, the level of awareness as well as knowledge about minority ethnic culture held by health professionals is a crucial constraint on improvements in health inequality. If health-education or health-promotion information is not delivered in a culturally competent fashion, recognising the need to adapt the message to the target audience, it

is wasted. Hipwell and colleagues have provided a useful paper on the Expert Patients Programme. For too long, health service providers have operated on the assumption that everyone knows how the health system works when the reality is quite different. The Expert Patients Programme helps to address this assumption and enable people to effectively take charge of their own health. Clearly, the tutors, who are themselves patients with long-term health conditions, need cultural competence training as much as clinicians, especially if this is to be, as it seems, the cornerstone of government policy. Otherwise, what could be a virtuous cycle of learning from experience and teaching others becomes yet another vehicle for exclusion and inequality. The experience of those who have recruited panels of people living with a specific condition, as in the case of the National Black Carers and Care Workers Network's efforts to develop a national panel of 'expert carers' (www.afiya-trust.org), is that it really is possible to recruit such experts from within the BME communities, and that they can, with appropriate support, be very effective advocates and trainers.

Community-based resources that include advocacy are discussed in our final research paper, in which Anneka Anderson reports on an ethnographic study full of rich detail explaining the strategies of migrant minority ethnic people to access the healthcare system in Aotearoa (New Zealand). Increasingly, there is recognition, even if it may seem rather late in the day, that knowing *how* to use something (like a health service, for example) is not universal, and may affect the way in which it is used. Perhaps not surprisingly, people's social capital or, more specifically, their social networks, play a crucial role. Communities have the potential to make a difference. Few health services really make best use of such networks or cultivate them in the interests of greater effectiveness and better health and, in paid-for systems of healthcare, more customers.

As earlier papers in *Diversity in Health and Social Care* have shown, we in the UK could learn much from the New Zealand approach to health services for minority migrant ethnic groups. What is perhaps most striking is the complex routes some patients took to find their way into the healthcare system, far from the stereotype, and definitely not good for their health or that of the public when considering tuberculosis (TB) as an infectious disease. We may also gain some sympathy for minority ethnic health professionals who are sought out as channels for healthcare, and thereby attract a heavy workload. If all healthcare professionals were culturally competent and more took the time to learn another language, maybe the work could be better shared and everyone would benefit.

Finally we come to our regular features.

Nisha Dogra has recruited Dr Khalid Karim to review a paper on the vexed causes of differential rates of diagnosed psychosis between ethnic groups and where

this is due to social class. The paper admits to a failure to look at parental socio-economic group, but argues that social drift between generations is not likely to differ between ethnic groups. We might respectfully beg to differ: as McGee's (2008) editorial in our last issue suggests, there are some groups, and not only the Irish, who appear to show negative social mobility and, as a general rule, despite the optimism expressed in our opening paragraphs, economic liberalisation and growth still show smaller dividends for most minority ethnic groups. However, the paper has some interesting support for the existence of a stress-related effect, and suggests a causative mechanism via a convincing clinical pathway involving the dopamine system, enabling the conclusion that 'xenophobia is bad for (our) health'. Karim also, incidentally, receives some support from another paper that our readers may not have seen, in our 'cousin' publication *Ethnicity and Health*, which reviews studies relating to the 'ethnic density' hypothesis – that living with more like-minded people increases your sense of safety and health (Pickett and Wilkinson, 2008). These two debates will continue, and we hope that our readers will contribute to them – and maybe send us their thoughts for publication.

As usual, Lorraine Culley's Knowledgeshare section contains a feast of useful resources. This quarter she has selected two reviews of rather different books that stretch the academic canon but may help to humanise the debate and be useful in passing on some sense of outrage to students. The theme of better treatment, as human beings, of refugee people is also addressed in Lay, Papadopoulos and Gebrehiwot's handbook on sexual abuse and unaccompanied asylum seekers (UMAS), a study which also tells a shocking tale and points to useful resources (available on the Internet through the University of Middlesex or the NHS Specialist Library (www.library.nhs.uk/ethnicity)). We also have a good practice report on chaplaincy services, by the head of the Multi-Faith Chaplaincy at Chelsea and Westminster, which might be seen as addressing some of the issues raised by one of our early contributors (Sheikh *et al*, 2004). And of course there is the regular update of new or recently found sites on the Internet in Diversity Webwatch.

To return to our opening thoughts, we wish to let our faithful readers know that, as from next year, the

journal is changing its name to reflect more accurately the focus of our coverage and our objectives. From henceforth, we shall be known as *Diversity in Health and Care* – not forgetting or losing entirely our concern for social care, but recognising that health is not just the absence of disease but a holistic concept that includes social, physical – and indeed spiritual – wholeness. Care, further, is delivered by many people and should be the concern of all, and responsive to all the aspects of diversity that we seek to celebrate. While part of the body or the community enjoys a different level of quality of living, then health is imperfect, and hence equality or at the very least equity and equality of expectation and outcome, if not of everything, is an essential element. We hope that the journal and its readers will continue to seek and disseminate examples of better practice that will contribute to the struggle towards the millennium goals of fairness and health for all.

REFERENCES

- Department of Health (2003) *Tackling Health Inequalities: a programme for action* (Cm 6374). London: Department of Health.
- Department of Health (2008a) *Health Inequalities: progress and next steps*. London: Department of Health.
- Department of Health (2008b) *Working for a Healthier Tomorrow, Dame Carol Black's Review of the Health of Britain's Working Age Population*. London: Department of Health.
- Department of Health (2008c) *Tackling Health Inequalities: 2007 status report on the programme for action*. London: Department of Health.
- General Medical Council (2008) *Personal Beliefs and Medical Practice*. London: GMC.
- Lewis I (2008) Equality in the health service. *Diversity in Health and Social Care* 5(1):5–6.
- McGee P (2008) Irish people and mental health. *Diversity in Health and Social Care* 5(3):175–6.
- Pickett KE and Wilkinson RG (2008) People like us: ethnic density effects on health. *Ethnicity and Health* 13(4):321–34.
- Sheikh A, Gatrard AR, Sheikh S *et al* (2004) The myth of multifaith chaplaincy: a national survey of hospital chaplaincy departments in England and Wales. *Diversity in Health and Social Care* 1(2):93–8.