

Editorial

Believe in change

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As this editorial is taking shape, a far more interesting event is occupying minds and media in the United States of America: the race for the Democrat party's nomination has become a two-horse contest. Barack Obama and Hillary Clinton are neck-and-neck, while the Republican party seems determined to nominate a 74-year old Vietnam veteran who happens (like all the previous holders of the Presidency) to be a white male – although perhaps distinguished by being potentially the oldest inauguree ever! Does this move, on gender, race and age, mark a breakthrough for the diversity agenda in the United States – and will it (like so many other innovations) take hold on the European side of the Atlantic? Readers from the south (whether on the Antarctic side of the equator or just in what was once called the third world) may be forgiven for scepticism and saying we did it first, but power still counts. Of course, counting matters too – so that the complex and convoluted systems of election required to bring this caucus race to a conclusion can still throw up unexpected outcomes, and confound the wishes of the electorate, no doubt.

From the United States also, we are pleased to be able to carry an interview with Professor Bob Like, a new member of the editorial board for *Diversity in Health and Social Care*, and an international expert on culturally competent care. His practice in New Jersey takes a pride in the appropriate use of language support and training of both interpreters and healthcare professionals, and the Center at the Robert Wood Johnson Medical School has become a beacon of excellence for training and research in North America. His interview (for which we thank the publishers of MDNG magazine for permission to republish) provides an extensive list of links to sites where similar work is going on, or at which advice can be found on these topics (from a North American perspective) which will complement the more European-oriented collection which our KnowledgeShare section has been developing.

In the interests of balance and diversity, we have a second guest editorial, from mainland Europe but written by another of our editorial board, Julia Puebla Fortier, who also has an intimate knowledge of developments in North America, and who co-ordinates the highly active and influential email discussion group CLASTalk-list – a community of practice spanning the United States and beyond, debating culturally and linguistically appropriate health services and linking users of resources for cross-cultural healthcare (www.diversityrx.org).

Nearer to home, can we really count on equality or is there still more rhetoric than reality despite the strong commitment expressed by the Minister in our guest editorial in the previous issue (Lewis, 2008)? Regrettably, the NHS healthcare watchdog, the Healthcare Commission, which announced a review of race equality in NHS trusts in November 2007 (*Healthcare watchdog to review race equality in NHS Trusts*, www.HealthCareCommission.org.uk), found some alarming failures of delivery in its initial scoping activity. The Commission was set to inspect over 40 NHS trusts to check on the actions being taken to meet their legal duty to promote race equality for staff and patients of all ethnic groups. As their audit of website postings suggests, high numbers of trusts still needed to do more simply to publish all the information they are required to under legislation on equality. It is to be wondered if, should they not have a published policy, they actually are committed to bringing about change – or have established that they are already meeting their duties in respect of delivery. If they are not counting it, can we be reassured that they are doing it? There was some sign of progress: in 2006 only seven trusts had published the required documents, while in 2007 there were 35 compliant with the law (but this is still less than one in ten of the 394 trusts!). However, as Ivan Lewis noted in his guest editorial, at least all the Race for Health trusts (<http://raceforhealth.org/>) are determined to meet this criterion, and that may provide a beacon

of excellence and an example that it can be done, if the will (or the carrot and stick) is there.

Nor is it only about race equality: only four out of five trusts had managed to publish their disability equality schemes – and only one in six were publishing impact assessments from their race equality schemes. Of course, this was only a quick check of their websites: it is always possible that the work had been done but not yet published, but surely, if you are doing the right thing it isn't too hard to let people know that? Maybe more stick is required, and we note that the Commission has also announced that, in future, any trust not publishing the information required under race equality law may be judged not to have met one of the Government's core standards. This could, in turn, affect their annual performance ratings (and their income!). In that respect, it is encouraging for diversity practitioners and advocates to note that there are several national core standards relating to equity and equality, assessed in the Commission's annual health check. These include:

- Standard C7e which requires trusts to challenge discrimination, promote equality and respect human rights
- Standard C8b which requires trusts to support their staff through organisational and development programmes which recognise the contribution and value of staff, and address, where appropriate, under-representation of minority groups
- Standard C16 which requires trusts to make information available to patients and the public on their services, provide patients with suitable and accessible information on the care and treatment they receive and, where appropriate, inform patients on what to expect during treatment, care and after-care
- Standard C18 which requires trusts to enable all members of the population to access services equally and offer choice in access to services and treatment equitably.

We modestly offer the pages of *Diversity in Health and Social Care* to all high-achieving trusts to trumpet their successes, and to all in the health and social care service sector as a place to describe, discuss and debate – and learn about – good practice in addressing the equality agenda. When we can all show that we are measuring, as well as talking about, equality across previously excluded groups, then maybe (as we hope to see in November 2008 in the United States) we will be able to believe that the change has happened!

In this issue, which was also being compiled during the week of St Valentine's day when it is reputed that a young man's fancy lightly turns to thoughts of love, we seem to have brought together a set of papers which explore that question rather more seriously. Members of both sexes have responsibilities and make choices,

and for some people, these are difficult, especially when belonging to marginalised and under-resourced communities – whatever our red-top tabloid newspapers may opine. Gina Higginbottom and her colleagues spell this out in relation to an often stigmatised group, young people in the BME communities. They have, sensitively and with a look not just at the youth but also at their parents and those who are supposed to be there to support them in the service provision sector, explored some key factors in decision making. It is perhaps not front page news that for much of the time their issues are not exclusive to the BME communities but are related to their developmental stage as teenagers, but it is important to note that these too are affected by experiences of poverty or educational underachievement. Further, it is important to recognise their contextual experiences as members of BME communities, which underpin some particular aspects of their experience as young people and impact profoundly on sexual decision making, and as they note, none of the Muslim young people became parents outside the context of marriage. That may not be unproblematic, but it certainly makes a difference.

By way of contrast, we also present a study from Shamser Sinha and colleagues in London, exploring sexual health with young separated asylum seekers in east London. This too is a much debated and stigmatised group: asylum seekers are at the forefront of political and media discourse and have been associated with issues such as criminality, religious extremism, terrorism, the spread of disease and competition for already scarce health, housing and welfare resources. There are also media stories about the sexual exploitation of this vulnerable group. Sinha and colleagues' interviews cast some light on this, including revealing the challenge of encountering more opportunities to meet potential partners in the UK than before migration and a near-total lack of access to sex education in the UK, coupled with insecurities over material needs and uncertainty over immigration status which render young asylum seekers vulnerable to sexual exploitation. We can see that there are all sorts of overlapping issues of stigmatisation and silence in discussion: sex, religion and parenthood (or youth itself), as well as asylum seeking, all of which are areas of sensitivity or stigma and censorship, as the next paper shows.

Sarah Carr, from the Social Care Institute for Excellence, examines how sexuality and religion present challenges for diversity management. Since sometimes mainstreaming these two agendas may create tensions between the advocates of one or other position within either the sexuality/gender stream and the various religions being considered. Carr writes honestly and frankly about her own personal position and the insight (and difficulties) with which this presents her. Many religious groups, for example, are clearly homophobic in outlook. Which identity or disadvantage

perspective has priority? Are there hierarchies of equality? What happens when social care providers consult with the leaders of religious groups, or where care workers are recruited from culturally distinctive groups and overseas, where the law as well as attitudes may differ from the UK? Interestingly also, Carr uncovers a treat-everyone-the-same (or colour blind) approach in relation to sexuality, as for race and culture. Clearly this is not a tenable position either. Nor should we shrink from discussing these awkward confrontations between value systems and their implications for implementation of equality legislation, regulation and guidance. We would welcome further debate papers on this and similar issues.

Continuing our attention to young people's issues, we present a knowledge review from the Unit for the Social Study of Thalassaemia and Sickle Cell, examining the needs and opportunities of young people with sickle cell disorder in the field of education. Hala Abuateya and her colleagues have brought together a substantial collection of writing in order to go beyond the usual clinical focus on how those living with SCD manage the psychological impact of their disease, and begin to engage with the broader social context of their lives. This must include, as would be argued by our earlier authors, the whole context of living, including interaction with disabling or racist structures. Abuateya and colleagues also suggest that this holistic approach could contribute to a wider understanding of the educational needs of young people from minority ethnic backgrounds and of young people living with chronic illnesses more generally.

On a completely different topic, although continuing the theme of dealing with chronic (long-term and life-limiting) illness, Redman and colleagues present a critical review of the literature on ethnicity, cancer and palliative care. They are properly critical of the limited value of much of the literature they located, and of the limited range of papers on this topic. The apparent lower prevalence of cancer in black and minority ethnic groups should not be an excuse to ignore the needs of this group. Indeed, cancer remains one of the top three killer diseases for BME people as much as for the white majority. Further, the similarity between cancer and other diseases in their implications for the healthcare of BME populations is striking and raises the question of why these patterns have not been addressed in this field too. In particular, they highlight issues of late presentation, poor referral patterns, ignorance about causes and management of cancer among minority communities and about culturally competent

care among healthcare providers and commissioners, all familiar conclusions from research and unfamiliar topics in the intervention and evaluation sector. Fortunately, the national Cancer Action Team has an equalities group chaired by Professor Mike Richards, the NHS Cancer Tsar, and this paper will provide useful ammunition for its deliberations, along with studies such as that conducted by Iqbal *et al* for Cancer Research UK (2008).

Last, but not least (and opening the batting in this issue), we are delighted to welcome a paper from one of the professions allied to medicine, discussing the neglected issue of culture and physiotherapy. Norris and Allotey cast a spotlight on the secret garden of physiotherapy, where practitioners face professional and personal dilemmas when working in cross-cultural settings and cross-cultural working is often ineffective, possibly because no-one has yet really thought what the culture of physiotherapy itself is. Is it, for example, totally dependent on western concepts such as *autonomy* and *individualism* as well as the objectification inherent within the medical model? We would welcome many more papers from the professions allied to medicine, such as occupational and speech therapy (as well as physiotherapy)!

Finally, observant readers will have noticed that the Knowledgeshare section has a new companion, in Nisha Dogra's *Did You See?* section. This provides our readers with the opportunity each issue to review a paper debating issues which we regard as central to our journal, but which they may have missed by not being subscribers to one or other of the mainstream professional journals. What is more, we have revised the presentation of our main papers. At the start of each, for busy people (and teachers!) we have added a little box which summarises what is already known in a particular field – assuming that anything is – and also, what this paper adds. We hope that this will be helpful and welcome your comments.

REFERENCES

- Iqbal G, Gumber A, Szczepura A, Johnson MRD, Wilson S and Dunn JA. *Improving Ethnic Data Collection for Statistics of Cancer Incidence, Management, Mortality and Survival in the UK*. Report for Cancer Research UK, Coventry: Warwick Medical School Clinical Trials Unit, 2008. Available at: www2.warwick.ac.uk/fac/med/research/csri/ethnicityhealth/research/crc.pdf
- Lewis I (2008) Equality in the health service: 60 years on. *Diversity in Health and Social Care* 5: 5–6.