

Editorial

Is anyone really listening?

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There is in English a phrase which might now be thought pejorative, but which seems well to describe the stately dance of policy development in relation to 'race' and health: a 'dialogue of the deaf'. As the year 2007 opened, David Nicholson, the NHS Chief Executive, found it necessary to write to the Chief Executives of all NHS trusts to advise them that each trust was individually responsible for compliance with the requirements of the 'equality agenda', and might face legal notices requiring compliance with the Race Relations Acts of 1976 and 2000 (Department of Health, 2007). These require evidence that action has been taken to tackle racial disadvantage and organisational barriers to access ('indirect discrimination'). The new Operating Framework *Equality and Human Rights in the NHS: a guide for NHS boards*, was published on 11 December 2006 and gives details not only about the expectation for race equality schemes, but also of the upcoming Disability Equality duty, Gender Equality from April 2007, and the need to take account of age, sexual orientation, religion and belief in the provision of services. To this we, and our guest editorial contributors from Scotland (Irshad, Worth and Sheikh), would certainly add language. It was therefore perhaps not so surprising that on 7 February, the Commission for Racial Equality announced a formal investigation into the extent to which the Department of Health and NHS had failed to meet their duties under the Race Relations Act 1976, as amended in 2000. There is much in the way of auguries – and no excuse for 'not knowing', since all the relevant documentation and guidance can easily be found on the NHS Knowledge Service's Specialist Library for Ethnicity and Health, in the section labelled 'Management and Policy' (www.library.nhs.uk/ethnicity).

In our last issue, we referred to the anniversary of the abolition of the Atlantic Slave Trade (at least in British law). Social justice is a global issue, and language is a tool through which it may be attained or denied. The US Office of Minority Ethnic Health acknowledges the

relationship between social justice and language and has sponsored the development of a patient-centred guide intended to assist organisations to provide services for patients who lack proficiency in English (Office of Minority Health (OMHRC), 2005). At least formally, language competency is a legal obligation in the United States (Fontes, 2005). Indeed, President Clinton even once signed an Executive Order stating that all agencies supported by Federal funds must provide services that are accessible to users with limited English proficiency – including health care. While the rights of European citizens to a 'fair trial' and understanding of legal charges in 'language they understand' are now well protected, we wonder what it will take to bring such an initiative into UK health and social care policy. Maybe we need another Wilberforce as well as the Equianos, Merediths and sundry other less well-sung heroes of the struggle against slavery.

After all, health and social care practice depends heavily on interpersonal skills and the ability to establish constructive and compassionate relationships with service users as the basis for therapeutic interventions. Numerous reports have emphasised the importance of good communication with service users, closely followed by strategies to bring about improvement. However, rather less attention has been paid to the languages spoken by service users, whether they truly understand what professionals are saying to them and the consequences of inadequate communication in this context. Experience in other fields such as law and criminal justice is not encouraging. In the past, non-English speakers have risked conviction and imprisonment for crimes they did not commit, a situation that the police and criminal evidence regulations and the Office for Criminal Justice Reform (OJCR) have sought to address (OJCR, 2006). We would not wish to imply that events of this kind are in any way peculiar to the UK. In 2001 a deaf charity worker in India received a 10 year prison sentence for possessing cannabis. His trial was in Hindi, a language he did

not know, and no interpreter was provided (BBC News, 25 June 2001). Now, the rights of European citizens to a 'fair trial' and understanding of legal charges in 'language they understand' have been well asserted and are enshrined in the European Convention on Human Rights (Sections 5 and 6) and the UK Police and Criminal Evidence Act 1984 (see Home Office, 2007). Consequently, the provision of interpreting is mandatory in legal settings. Moreover, interpreters must be properly qualified and competent. Nevertheless, health and social care professionals seem to have been slow to recognise the possible consequences of poor communication with patients who do not speak English. A recent article in the *British Medical Journal* has provided a reference to the only published example that we know of in which the risks of adverse events following consultations by patients with poor spoken English are discussed (Divi *et al*, 2007). This American study examined adverse event data in six hospitals over seven months, and examined them against the English proficiency of the patients involved. Nearly twice as many of the events affecting those with limited English proficiency led to physical harm, and more than half of these were deemed to be due to communication errors, whether because of poorly interpreted advice or questionable assessment of patients' needs. However, we are certain that there are many more examples to be found, given that the ease of modern travel, migration and resettlement inevitably creates opportunities for encounters with foreign health services in which few, if any, staff will speak the language of the traveller.

Clearly any consideration of equality in relation to diversity must include the provision of language services that enable everyone to access the health and social care they require. There are, no doubt, some people who will argue that such provision is a waste of money; that the £100 million spent on interpreting services in the UK could be better spent on other things; that the inability to speak English marks out individuals as *not one of us* and thus not entitled to the use of *our* services. Such arguments are flawed for several reasons. First, there are indigenous linguistic minorities within the UK for whom English is not a first language and who, if forced to rely on it, may struggle to communicate effectively. Second, within every expatriate community around the world there are individuals who make no effort to learn the dominant language of the place in which they live, and seem to take an almost perverse pride in this. Castigating them for their failures when they are most in need of help is neither humane nor likely to promote a change of behaviour. Third, learning to speak another language requires far more than the substitution of one set of words for another. Each language is an expression of a way of being in and interpreting the world – a factor that is far more likely

to affect the quality of communication than the actual choice of vocabulary. It is this movement between two views of the world that can make speaking a second language and interpreting such demanding tasks.

Bilingual writers provide insight into the degree of complexity that this requires. For example, Wierzbicka (1997), a linguist, has described her experiences as a speaker of both Polish and English and the constant changes required as she moves, within herself, between one language and the other. We do not need to remind readers that the current 'new kid on the block' is the recent wave of Polish and other eastern European migrants providing essential services in cities and rural areas alike. Wierzbicka argues that not only do the two languages have different conventions about expressing concepts such as the time of day, but they also have distinct conversational styles. To illustrate this point she draws attention to the Polish style of conversation in which there is frequent use of the imperative forms of verbs; in English, this conversational style is regarded as confrontational or even rude. Thus in moving between the two languages, the speaker must make a series of decisions about how best to convey thoughts and ideas and what to omit. Similarly, Hellman (1989), whose first language is English, describes her difficulties in learning English patterns of voice control and modulation. For both these writers the sheer effort required to take account of the functional, cultural and conceptual differences between Polish and English creates high levels of intrapersonal conflict. Finally, lack of investment in the provision of interpreting services staffed by suitably qualified people places an added burden on bilingual staff who have received no preparation for this responsibility and who may lack the vocabulary necessary to adequately explain health and social care matters. Bilingual staff are often happy to do what they can to help service users and colleagues, but they can also feel overwhelmed by the responsibility and experience high levels of stress from trying to fulfil roles for which they are not qualified (McGee, 2000).

In this context, we are pleased to introduce our guest editorial which also takes up some of the arguments aired in a recent *British Medical Journal* debate (Adams and Jones, 2007). There clearly is a cost in working across languages, in terms both of time and expertise, but this pales into insignificance in the light of the human rights implications, and the potential risks of misinterpretation and failure to follow or agree a treatment plan. Irshad, Worth and Sheikh present many arguments that are familiar, but it may be worth underscoring the fact that the UK population is in a constant state of flux. They, like many of our authors, refer to 'BME' populations: this term (the acronym for black and minority ethnic) includes many 'new' minority groups originating in Africa, east and central Europe and other parts of the world,

as any casual observation of both inner London and remoter parts of rural Britain will show. Nor should we forget that, as earlier European migrants have also demonstrated, when people get older they may lose what fluency they have acquired in the majority language. Irshad and colleagues make a convincing case for the value of investment in services for ITALS – interpreting, translation and language support – and they present an effective demolition of the traditional ‘use a family member’ alternative. It is not only the poor we have with us always: there is also the stranger and the person who cannot speak our language – or perhaps whose language we cannot speak.

Also from north of the border, Mullen and colleagues in Glasgow bite into the question of factors affecting ‘going to the dentist’ across a range of ethnic groups including the white Scots. They present a sound summary of the considerable published evidence base on ethnicity and dentistry. It will not surprise many that a visit to the dentist was not seen as a pleasurable or popular pastime, but younger people do seem more likely to take active steps to preserve oral hygiene or appearance, so things may be changing. Interestingly, while Chinese people prefer Chinese dentists, some South Asian women would prefer a white male to a Pakistani male if they cannot have a gender-matched, female professional. And while there is some acculturation, younger people from migrant backgrounds still have to accompany their older family members on their appointments, and hence would prefer dentists who could speak the parental language. The dentist’s chair is no place for an interpreter!

Ryan and an international cast of colleagues report on a multinational study in Scandinavia, Poland and the UK of the stresses of working for mental health services. This is, as ever, topical, and while more statistically challenging than most of the reports we carry, the paper merits close reading. Burnout is an international phenomenon, and while it has many components it can be combated if properly understood. The paper also shows some interesting sex and national differences in needs, and has relevance both to the care of one’s staff and also to service delivery. It is clear that prior training (not *post hoc*) and increased experience can be helpful, as is a feeling of being able to make a difference – but (as UK colleagues at least will aver) reorganisation is a hazard. It might also be worth trying to spot signs of low self-confidence, lack of assertiveness and inability to set limits, in new recruits – since although it might be nice to have meek and hard-working staff, who thrive on their managers’ approval, they are the most likely to become burned out and create problems later on. Unpaid overtime and excessive work-related travelling are also false economies. It would be nice to think that this research will improve the work conditions of some healthcare staff.

Public understanding of science is at best a mystery, and if it becomes misunderstanding, can be at worst a potential hazard to those who miss out on access to the potential benefits of ‘progress’. There is no benefit in scientists developing ‘new reproductive technologies’ if no one understands or knows of their existence to make use of them. Culley and colleagues, however, challenge the familiar ‘deficit model’, while not denying inequality in access to information, by showing the subtleties and complexity of knowledge about infertility among South Asian populations in Britain. On the other hand, it is far from clear that healthcare professionals are as well informed or as sensitive to the diversity of needs and expectations in those South Asian communities. Without that better understanding, they are poorly placed to offer support, care or even access to the range of treatments that exists, especially when information is not made available in languages and formats appropriate to potential users. This is perhaps ironic when those of us with long memories recall the plethora of targeted ‘health promotion’ materials from the 1970s and 1980s aimed at limiting fertility among South Asian migrants (Bhopal and Donaldson, 1988). While it is true that South Asian communities do value children highly, and that childlessness is a highly stigmatised state, the team note increasing acceptance of at least a delay in childbearing and perhaps a fall in expected total family sizes. Asian women were not ignorant of the causes of infertility, but may have been more constrained in their ability to express or discuss this publicly. Neither were they unwilling to seek help – the stereotype of the fatalistic Orient is quite clearly fallacious, but religion remains a reassurance and comforting to those who are unable to bear children while not preventing them from seeking medical solutions. However, a number of barriers, including knowledge and language skills, interfered with this process. And, because of the social stigma of infertility, being *seen* to seek remedies for it was, because of the revelation required, another potential hazard to negotiate. Another one appeared in the focus groups – and maybe we should not have drawn attention to this as Patricia Hewitt, the Health Secretary, has recently been criticised for stating something similar – but it remains true that some Asian informants expressed concern about the confidentiality of their consultation with an Asian doctor. Overall, however, the conclusion of the study is that there is a need for more active social marketing of the services to treat infertility, alongside making those services responsive to the specific needs of minority ethnic groups who try to take them up. More information alone is not enough.

For many people, ‘ethnic health’ means those diseases and conditions that are most commonly seen in people from minority ethnic groups. Clearly, everyone has an ethnicity and therefore a predisposition to

certain ethnicity-related conditions, but the fact remains that the health services have historically been slow to provide for the needs of minorities. While the NHS Screening Committee has now adopted a policy of universal availability of screening for sickle cell and thalassaemia (the most commonly cited 'minority ethnic' diseases), this has followed many years of research and campaigning (www.sickleandthal.org.uk/whatsnew.htm). Dyson's paper gives an indication of some of the problems of implementing such a policy in areas where fewer BME people are to be found. Even when carefully designed questions are used in a context of a research-based intervention, at-risk parents may not be offered the tests they need unless more training is given. Indeed, there remains (again, even within the 'halo' of such a research study) some reluctance among NHS staff to collect ethnicity data – an issue that we shall return to in a paper by Jones and Kai (2007) in the next issue of this journal.

Dyson and colleagues did find that, despite the general preference among social scientists to offer open 'self-definition' questions about ethnicity, a well-designed census-type question offering predefined categories was more effective and reliable in identifying people – almost by definition from BME origins – who were at risk of one of the haemoglobinopathies. It is also clear that even within the context of this research there were some practitioners (and indeed a whole maternity unit) where routine ethnic monitoring data were not being collected, nearly 10 years after this became a requirement for all inpatient care episodes (Department of Health, 2005). 'Ethnicity' is not the same as either 'colour' or nationality, and failure to recognise this can, as Dyson and colleagues show, have a potentially serious impact on care delivery. At least the categories devised for the 2001 census do seem to address this need and be reliable and acceptable, even though Dyson and team demonstrate a higher 'detection rate' for their own more complex questions.

Judy Davison adapts another qualitative research approach, the often neglected use of life histories, to examine the effects of abuse on women's propensity to drink (alcohol). In this, she turns the conventional paradigm (men drink, assault women) upside-down and reveals alcohol use to be a coping strategy for problems which may have much greater salience for the subject. We should know that women may be different from men, but we rarely explore this issue in relation to problem behaviour in a way that enables better interventions and support. Further, the research method itself is shown to be an empowering and 'feminist-appropriate' strategy, which like many of the papers we carry, allows and highlights the voices of the oppressed and the service user.

Meanwhile, we can report some slight progress or at least, an opportunity. Knowing that many of our

readers are already convinced of the merits of patient profiling and ethnicity monitoring, and that one of the front-runners in the French presidential race has espoused the cause of ethnicity recording in France (Chrisafis, 2007; against all odds, it must be said), you may be aware that a UK Census Test will take place in 2007. The questionnaire for the 2007 Test, published on 31 October 2006, shows the questions on ethnic group, national identity, religion and language at the latest stage of development. However, these questions are by no means finalised. It may not yet be too late to make responses to this consultation, which will inform further question development in 2007. The Office for National Statistics (ONS) will then make recommendations in 2008 on the questions for the 2009 Rehearsal and 2011 Census, which will then need to be agreed by Parliament in early 2010. The Census Test questionnaire is available at: www.statistics.gov.uk/censustestquestionnaire. The 2001 questionnaire, against which current data will need to be compared, is at: www.statistics.gov.uk/census2001/census_form.asp. The report on the 2005 consultation is available at: www.statistics.gov.uk/about/consultations/ and the ONS review of ethnic group, national identity, religion and language considers issues such as: acceptability of terms, categories included and excluded, collecting national identity data separately from ethnic group data, continuity with 2001 data on ethnic group and religion, and allowing multiple responses in the ethnic group question as well as the level of information required on languages. All of these are vital issues for discussion – and are at present being subjected to lively debate on the Minority Ethnic Health electronic discussion network (www.jiscmail.ac.uk/minority-ethnic-health). Latecomers can catch up via the archive of that list. What we do not ask about or measure is often ignored, but is seldom unimportant.

Our regular Knowledgeshare section in this issue presents us with some challenges as well as access to good practice and information. In particular we should like to draw readers' attention to the challenge of facing up to feelings, fears and myths around sexuality in providing social care – and how this might interact with the complexity of working with learning disability. At the same time, we can point to developments in policy and practice in mental health, and enable readers to share what is provided as a briefing to our legislators through the parliamentary office of science and technology in Kaveri Harriss's succinct summary. Further, a report from the Genetic Information Group about their Translation Project provides additional evidence of the importance and risks of working across languages. And finally, maybe we can conclude with an observation made by Chief Rabbi Jonathan Sacks, as broadcast on BBC Radio 4's Thought for the Day on 26 January 2007 (Holocaust

Day): 'May we never forget that the people not like us are people, like us'.

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