Editorial

Can't count, won't count

Mark RD Johnson MA PhD Dip HE (Warwick)

Editor, *Diversity in Health and Care*; Professor of Diversity in Health and Social Care, Mary Seacole Research Centre, De Montfort University, Leicester, UK

Paula McGee PhD RN RNT MA BA Cert Ed

Editor, *Diversity in Health and Care*; Professor of Nursing, Faculty of Health, Birmingham City University, Perry Barr, Birmingham, UK

This editorial was composed against a backdrop of media reports from a shocked Japan, beset by earthquakes, tsunami and radiation pollution from a set of damaged nuclear power station reactors. Rather than illustrating diversity, perhaps, the scenes make one reflect on the essential unity of humanity - the universality of grief and terror, and the underlying resilience and mutual solidarity that are found in very different societies. However, one key theme does keep emerging, namely the importance of numbers, manifested as the desire to quantify (e.g. a Richter Scale of 8.9, a city of 170 000 inhabitants, a 30-metre-high wave) and a need to know how many or how few casualties and survivors there are. This too is a universal issue and one which links back to diversity, since only by counting and classifying ('taxonomy', one of the earliest elements of Greek philosophy) can we know exactly how diverse we really are and how much we share. When faced with threats to our very survival, it is not our differences that matter, but our ability to cooperate. In the early days of our species, when there were far fewer of us, survival depended on working in groups and sharing tasks such as childcare, thus freeing up some adults to hunt and forage to stave off starvation for everyone (Macleod, 2011). When faced with catastrophe, people do not fold up, exhibit signs of hysteria or act only in their own self-interest. As we have seen in Japan, and earlier this year in New Zealand, the opposite is true, as people quietly help each other to rebuild their lives. When the Luftwaffe started to bomb Britain there were fears that society would break down. However, it didn't, nor did it do so subsequently during the IRA bombing campaign and the 2007 bombing in London. Hollywood has given us a false image of ourselves as barely a hair's breadth away from savagery when report after report shows that this is far from true. People's immediate response to catastrophe is to help each other (Hari, 2011). The differences that previously seemed so important fade into thin air. Of course differences matter. At the very least they make for a more interesting world but, as we are well aware, the emphasis that we put on them is often way out of proportion to their merits. We can do better than this, and Japan and New Zealand have shown us our true selves.

Indeed, another picture of us is about to be produced! Alongside the editorial keyboards sits the 2011 Census form - a 31-page form containing 42 questions for all members of the household, asking about age, sex, marital and socio-economic status, disability, ethnicity and faith, as well as employment, type of housing and many other matters. This must be completed, by law, before this editorial has to be submitted to the publisher! However, in the world outside people are protesting and refusing to complete their returns, afraid that the data may be misused or manipulated to their disadvantage. Echoes of the Holocaust are evoked, and attention is drawn to the commercial links of the agency charged with collating the survey returns for the Office of National Statistics. But this is an old song. It was clearly heard probably as early as the 19th century. Certainly in 1981 and 1991, when we were first discussing the inclusion of an ethnicity question (Royal Statistical Society, 1983), fears were expressed, not least by the Jewish community (although, as was pointed out at the time, Hitler's legions found much easier ways to identify and locate people of Jewish background, and few of these were truly 'evidence based'). The other side of the coin is that many local authorities have complained that their services have been underfunded because of the failure of the census (and subsequent updates of population size and need) to adequately record population size and diversity - perhaps because of the acknowledged undercounting of (or avoidance of reportage by) young black men or other groups scared of officialdom. Yet in the 1970s in America, where racism was still very overt, the national leadership of the minority communities stood up and paid for advertisements in buses and the media using the title of the 1968 James Brown song: 'On census day say it loud and clear: I'm

black, I'm proud and I'm here! Be counted, baby' (Dubs, 1980; see also Howard, 2004), thus generating irrefutable data and evidence both of their importance to the national economy and of their under-privileged position. The 2011 census in the UK, for the first time (at least outside the Celtic nations), will also ask about 'main' language and fluency in English, perhaps providing evidence for those who seek greater access to, and provision of, interpreter support and translation ('ITALS'). If people refuse to be counted, their views and needs will also go unreported.

It is also perhaps worth noting that the Government of India has now produced its first report on the Census of India - an enormous undertaking! The latest statistics reveal that the resident population of India alone (more than 1.2 billion people) represents more than 17% of the world population. This does not include the number of people of Indian origin in the diaspora, or indeed the population of the neighbouring states that were once part of 'British India.' Their census refusers might have found it hard to avoid the detailed scrutiny of more than 2.3 million enumerators, and would have been asked even more questions, including items on the availability of a computer and the Internet! However, the results reveal some disturbing findings, including the fact that female infanticide is still a curse. There are only 914 girls for every 1000 boys aged under 6 years, which is worse than the situation 10 years ago, when the ratio was 927 girls for every 1000 boys. The change is partly attributed to the increasing availability of non-invasive and relatively cheap (if not always accurate) tests such as those highlighted by Osipenko and Szczepura (2011) in our previous issue. Not surprisingly, in view of the implications (including the stimulus for trafficking and prostitution), the government has promised further action to combat this scandalous situation.

Some people who have refused to be silenced, and who have made sure that their groups of origin and their needs have been noted and attended to, were also recognised this year. One such individual is Dr Suman Fernando of the University of Kent in Canterbury, who has been honoured with a Lifetime Achievement Award for Culture, Race and Mental Health by the University of Toronto and Ontario Institute for Studies in Education (http://cdcp.oise.utoronto.ca/ 2011_Conference. html). This recognition of a lifetime of distinguished professional contribution to the theory, research and practice of multicultural and diversity psychology and counselling is well deserved (see also www.sumanfernando.com). Other individuals were singled out by their peers and communities in Britain for recognition at the first 'Afiya Trust Awards' ceremony, designed to highlight the role of community champions in progressing the health of diverse communities. Familiar names, acknowledged

for their role as 'celebrity champions', included Nina Wadia and Lenny Henry, and a well-deserved award (named in honour of Lord Michael Chan, a paediatrician whose untimely death robbed us of a doughty campaigner and one of the first BME People's Peers) was presented to Peter Scott Blackman, a former musician and first Chief Executive of the Afiya Trust. Well-known campaigners such as Beverley de Gale, co-founder with Orin Lewis of the African Caribbean Leukemia Trust, were also recognised, but shared the stage with less well known but no less worthy recipients such as Richard West, who is deaf with a learning disability and is Chair of the National Advisory Group on Learning Disability and Ethnicity, and Shamima Essat, a Muslim woman with a learning disability who works as a Support Assistant at Valuing People, Leicester City Council. We confidently expect that some of the activity noted at these awards will be reported as research and practice in the pages of this journal, and we hope that future generations may recognise the role of some of our other contributors. We shall now consider the contents of this issue.

In opening, we welcome a guest editorial from two prominent members of the Muslim medical community in Britain, both former advisers to the Muslim Council of Britain, who speak out here about the issue of child protection. None of us should be afraid or ashamed to take action to safeguard the vulnerable, but all too often, and in most communities, there is a conspiracy of silence because of a desire to protect the good name of the culture or faith, or perhaps because people really cannot believe that members of their own group could act in ways that so completely contradict their (and our) fundamental beliefs. It is reassuring and helpful to know that Islamic bodies are standing alongside the Christian churches in tackling the evil of child abuse within their own ranks.

We open our research papers with a report by Roy and colleagues from North-West England, which describes the development of a service to promote autonomy and, by anticipating them, to prevent crises. They show how, by using robust research methodology (consisting of 11 focus groups), a better understanding of concepts of well-being and help-seeking behaviour enabled the development of a personalised social care support system for adults. Fortunately, their local authorities recognised the need to address the wider determinants of health and to ensure that health gradients did not become steeper and deeper. A key element was inclusion as a 'first contact' of workers such as librarians who would be familiar to users but not perhaps immediately readily identified with welfare provision. Equally, informants emphasised that being able to participate in communitybased activity was a key element of their perception of well-being. This issue is not always highlighted in health and care plans. Could this perhaps be because

the 'Big Society' means different things to different people? We look forward to seeing an evaluation of the operation of the new service, to find out whether it did follow the advice that was so freely given, and whether this worked in practice.

Our next paper, by Robinson and colleagues, also looks at the ways in which people with needs come into contact with services. Some of the themes of the first paper, including both stigma and suspicion or mistrust of services, are picked up again here in relation to men's experiences and needs for mental health support. Interestingly, and unusually, the paper addresses not only the views of black (African Caribbean) men, but also insights from Indian, Pakistani, Bangladeshi and Chinese focus groups. It is not that there is a lack of recommendations in this field, but few studies have cast their net so wide, to present a consistent and comparative view across minority ethnic groups, and find that there are many common themes. However, often these are expressed differently, or need to be addressed in culturally specific ways. (To use a suitably 'male' hegemonic culturally situated example, think of football played with differentshaped balls or subtly different sets of rules, whether Australian, League or Union!) Now we need to find effective 'recovery model' examples of interventions to which to apply these insights.

Moving overseas, we have a paper from Shoba Nayar in New Zealand, who considers the role of children, much mentioned in the previous paper, but here considered in relation to the well-being of Indian women settlers. Again this paper highlights the salience of belonging to a collectivist society rather than an individualistic one, and makes recommendations for development services that are better tailored to the needs of their prospective users. Children, as those who have had them will know, significantly restrict one's freedom of action, but may also introduce one to unfamiliar ways of being and doing. Surprisingly, the author notes that this has been little explored in research (perhaps we are all so exhausted after the experience that we want to move on).

Her 25 female respondents were divided into three groups. Those who had no children on migration had made a life for themselves in a strange land before having to consider how to reproduce, or at least pass on, their original culture to the next generation. Those with younger children found that the process of cultural reproduction was itself an important activity that both supported and placed stresses on well-being. It also led to very direct contact with the institutions of Aotearoan (New Zealand) society, such as the mother and toddler group. Those with older children, on the other hand, valued their support in negotiating the unfamiliar. These insights will be of considerable use to family services in thinking about how to work with newcomers.

Diversification of the health and social care workforce is a key response to the need to meet increasing demand and find not only new workers but also new skills for delivering care. Much has been written (a lot of it in this journal) about the role of minority ethnic and migrant workers. Manthorpe and her team, through a careful analysis of the National Minimum Data Set (NMDS) on the social care workforce, have identified a new trend, with 'third-age' or 'return-towork' staff playing an increasing role in delivering services, often to their own peers. Of course new government regulations on retirement age are now raising the bar for us all, but the picture presented here shows not only that the facts have anticipated the policy, but also that there are considerable implications for the employers.

It is noteworthy that the 'third sector' shows a particular affinity for, or use of, older workers as employees as well as volunteers. The 'private' sector, on the other hand, is either missing out on this source of recruits, or perhaps choosing to ignore it. There are no data available from the NMDS on what people in these roles (or their users) actually think about the situation, and apparently very little has been published on this issue. We feel that there is an opportunity here for future papers to be submitted for our consideration, especially if they also address questions relating to impairment/disability and culture.

Returning to the theme of our first two papers, David Truswell reports in a Practice Paper on the role of BME communities in the implementation of a dementia care strategy for London. Given the current lack of robust research on this issue, practical action that moves the agenda forward is welcome, and demonstrates that effective action need not be paralysed by fear of the unknown. There is plenty of understanding and informal research capacity or intellectual resource available within the black, minority ethnic and refugee (BMER) communities, if agencies are prepared to reach out and trust rather than complain about people who are 'hard to reach'! Furthermore, the use of electronically available resources such as that described here, or the Health Promotion Agency site on migrant health (www.hpa.org.uk/migrant healthguide), building on the model established by the Centre for Evidence in Ethnicity, Health and Diversity (www.library.nhs.uk/ethnicity, but please keep an eye on the Knowledgeshare section of this journal for future developments), should help to overcome the usual complaint or excuse of service planners in relation to minorities, that 'they don't know where to begin.' Truswell and the NHS 'Commissioning Support for London' group have shown what can and should be done in this respect.

The issue closes with our three regular feature items, all of which present novice authors and practitioners with an opportunity to get a foot on the ladder of

66 MRD Johnson and P McGee

publishing, or to critique research, policy and practice from a grounded perspective, by challenging a research or policy paper (Did You See?), reflecting on an incident in the everyday workplace (Practitioner's Blog), or writing a short description of some innovation or attempt to develop services (Knowledgeshare). Perhaps new entrants to the field could regard this as part of their continuing professional development!

REFERENCES

Dubs A (1980) Hansard Commons Report, Series V 983:col. 1328.

- Hari J (2011) The myth of the panicking disaster victim. *The Independent*, 18 March.
- Howard K (2004) Constructing the Irish of Britain: ethnic recognition and the 2001 UK Censuses. Working Papers in British-Irish Studies No. 37. Dublin: Institute for British-Irish Studies, University College Dublin. <u>www.ucd.ie/ibis/</u> filestore/37_kh.pdf
- Macleod M (2011) Kindergarten co-op: how babysitting made us brainy. *New Scientist*, 16 March.
- Osipenko L and Szczepura A (2011) Non-invasive fetal sexing: medical test or a new tool for sex selection? *Diversity in Health and Care* 8:37–44.
- Royal Statistical Society (1983) Discussion on sources of statistics on ethnic minorities. *Journal of the Royal Statistical Society* 146:108.