

## Editorial

# Dual jeopardy or double pride? Disability, difference, diversity and the gentle art of handicapping

Mark RD Johnson MA PhD Dip HE (Warwick)

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

This summer the Olympics, and to an even greater extent the Paralympics, celebrated diversity and equality in new ways that gripped the world. They were the first Olympics to which every participating country sent women athletes as well as men, and the first in which people usually labelled as 'disabled' demonstrated their ability to compete against their apparently 'able-bodied' peers. These games have certainly shown us that exceptional people come in all sizes and shapes, and transcend their hidden differences, including blind footballers and 'intellectually disabled' swimmers. Oscar Pistorius, a double amputee, may not have won his races in the 'main' Olympics, but his admirable persistence in pursuing his dream of competing has opened the doors between this competition and the Paralympics. Old notions of 'disability' have been challenged and consigned, we hope, to the scrapheap, as 'disabled' athletes revealed their abilities in the Paralympics with trial times equal to or better than those of their 'able-bodied' qualifying peers in a riveting series of events. This has led to some renewed debate about what actually constitutes 'disability.' Oscar Pistorius was first denied the opportunity to race in the Olympics because his legs had been amputated. Having proved that he could run as fast as men with two natural legs, he then had to contend with the bizarre argument that artificial limbs created an unfair advantage. Many would have given up, but eventually not only was he allowed to compete, but also, in doing so, he has changed a bit of the world for ever. At previous games no one could have imagined that athletes with 'disabilities' could or would ever take part, and at the moment many Paralympic athletes will have to continue to pursue their chosen sport following the complex series of provisions intended to ensure fairness. The challenges presented

by each athlete's body are unique, and trying to ensure some sort of parity between competitors can be difficult. Nevertheless, the achievement of Pistorius raises hope that, in sport at least, the long-established distinctions and inequalities between 'us' and 'them' are starting to erode.

Sadly, other forms of difference and inequality continue to give cause for concern. Several Olympic/Paralympic winners had to convince the Borders Agency (UKBA) that they were bona fide competitors before they were allowed to enter the UK, and to return home as heroes. No doubt individual UKBA staff did not intend to offend or create uncalled for difficulties. Nevertheless, institutional barriers (and, indeed, organisational cultural incompetence) in all sectors continue to underpin the multiple ways in which discrimination occurs and people are disadvantaged. Sexuality and sexual orientation are other diversity strands which provide particular examples of the ways in which these processes occur. Even under enlightened regimes, knowledge and understanding of sexual differences is sparse. Those born with indeterminate or uncertain sexuality, who do not fit neatly into the categories of male or female, are poorly understood by most of the population. In some instances the differences are easily discernible, but in others differences may only come to light as the individual matures and realises that their body is not as it should be for them to express their sexual self. We begin this issue with a guest editorial by Katherine Johnson and Kath Browne, who have researched the experience of transexuality and argue that our systems are pervaded by an 'embedded heterosexism' (Johnson and Browne, 2012). However, we need to go further in unpacking and specifying the details and dimensions of gender non-conformity (as we also have to examine

shades of, and internal discrimination between, the various categories of ethnicity and disability).

Gender non-conformity is not just about 'LGB' but also relates to trans and intersexed people, and maybe also those who are sometimes referred to as 'questioning.' We should note that here, too, there may be problems of disclosing or self-identifying, as is suggested in our CPD feature on equality monitoring, where some agencies actively suppress or hide some categories in order to avoid or prevent discrimination, stigma and possibly shame. In countries such as the UK, considerable and demonstrable progress has been made in reducing ignorance and prejudice directed towards lesbian, gay and bisexual (LGB) people, although much more is needed, especially to support young people who may be exposed to bullying ([www.youthchances.org](http://www.youthchances.org)). Nevertheless, outside the UK and some other relatively enlightened states, people are still obliged to flee to other countries because simply being who they are may incur torture and/or death. Bob Cant reminds us of the precarious nature of enlightenment by looking back, not very far, to the events and forgotten victims of the Holocaust (Cant, 2012). The impact of such experiences, whether individual and personal, or collective and historical, remains an issue for mental health and well-being for members of all minoritised and disadvantaged communities. The freedom to flourish that was so much a part of life in Berlin in the early 1930s was rapidly destroyed by a new government. Such changes are still possible in any state. This is why it is so important that we remember Holocaust Memorial Day (to be marked on 27 January 2013), for which we offer this issue of the journal as our specific contribution (as it is being compiled during November 2012), otherwise known as LGBT History Month (<http://lgbthistorymonth.org.uk>). New histories, of which LGBT is an example, are so important because few older people with direct recollection of such events as the Holocaust are still living, and it is vital that the causes and facts of previous discriminations are not lost and made deniable. Indeed, people in East and Central Europe are now striving to document the secret histories and oppressions operated by the police state regimes of the recent past, in the face of considerable opposition, perhaps from those who have secrets of their own to conceal (see the Slovak National Memory Institute and its travails as recorded at [www.upn.gov.sk/english/links](http://www.upn.gov.sk/english/links)). As we rely increasingly on the Internet and social media to spread the word and forge a more open society, there does seem to be a fashion for exhibitions based on multi media (film, extracts from interviews and music or drama). Maybe it is the world we live in now, but it is also much more immediate and real, and creates a different connection to traditional, written forms of presentation. However, we are and must remain a print journal (even if we are

increasingly available as a web-based presence). That is why we for the first time here have begun to offer authors the opportunity to include more detailed tables and resources on a website linked by URL from their articles (as has been done in the paper by Higginbottom *et al*, 2012; see below).

In our first research paper, MacDonald *et al* (2012) review the healthcare of another hidden minority, namely those who are incarcerated in prison (whether for the protection of society, their own re-education, or simply as a punishment for transgressing the 'commonly accepted rules of society'). Human rights approaches dictate that 'even the least of these' retains some element of human dignity and entitlement, not least to adequate healthcare, or else the hope of re-education is likely to be in vain. As these authors set out to show, provision of adequate 'throughcare' is an essential element of successful reintegration into society. Why then does it seem to be so hard for one state to learn from another, and a suite of common principles and practice adopted? Are 'your' or 'our' commonly accepted rules of society incompatible with 'mine' or 'theirs'? Do we in fact have very different priorities? Surely we share at least a self-interest in reducing re-offending, and this points to one simple way forward.

Turning from the 'Old World' of Europe to the 'New World' of North America, we have two papers which continue this theme and that of 'language.' Higginbottom *et al* (2012) present a systematic review that aims to synthesise and present in one place a concise summary of the evidence relevant to migrant mothers' maternity care in Canada. Politically, the case is strengthened by their observation that, startlingly, by 2031 one-third of Canada's population will belong to a 'visible minority' (or 'BME' ethnic group). Key recommendations are highlighted, reflecting themes often aired in this journal, such as the need for proper input and support from service users in service design, and the use of interpreters, translation and language support (ITALS) in service delivery to minority populations, including better understanding of cultural expressions of distress. Their summary grid, which presents the details of 30 selected papers, can be accessed on the publisher's website and provides further evidential support for these ideas.

In another paper, from south of Canada's border, May Lau and her co-authors look at the influence of belonging to a minority language group on disparities in the health and healthcare of US adolescents (Lau *et al*, 2012). Health inequalities associated with 'limited English proficiency' (LEP) or 'non-English-speaking background' (NESB) in Anglophone societies are well documented around the world, but primarily in connection with the health of adults (and sometimes children). Adolescents (aged 10–17 years) are probably more likely to be bilingual, to attend

schooling in the dominant language, and are often used as interpreters by family and under-resourced or ill-advised clinical staff. It is probably also true that similar arguments apply to non-fluent speakers of other languages in states where the dominant language is not English, although this has not been widely researched, partly because of the use of English as an international lingua franca among professionals and migrants! In the USA, where current presidential campaigning has frequently been conducted in Spanish to attract votes from the one in eight members of the population who are of Latino heritage, it is alarming to learn that Latino/Hispanic adolescents are still significantly disadvantaged in terms of healthcare and health outcomes, as well as poverty, educational levels and use of preventive and health maintenance services, but that poor records are kept of language need and support provided.

Finally, considering the infrastructure of diversity management and inequality reduction, we include another paper from the study of cancer research data, looking at the healthcare professional's perspective on ethnicity data collection in the UK (Iqbal *et al*, 2012; see also Iqbal *et al*, 2009). The authors had previously noted that a major problem in collecting data to enable action on health inequality was the perceptions and behaviours of healthcare professionals, and in this paper they seek to unpack these. The barriers identified here point to areas where the development of training materials is seen as vital, since less than a third of their respondents reported that their organisation provided ethnic monitoring training. It is clear that health professionals need to know why data are collected, and to be briefed in its collection, before any progress can be made. The authors conclude that the failure to use those data that are collected is a disincentive to both professionals and patients, and they recommend that using the data we already have, irrespective of its quality and completeness, will encourage improved collection in the future by highlighting any inadequacies.

In the light of this paper, we felt it incumbent on us to act, and we therefore present as the final 'Educational Resource' in our CPD feature for this year a short summary of advice and resources regarding the conduct of equality and diversity monitoring, not solely on the subject of ethnicity, but across most of the diversities of our title (Johnson, 2012). We hope that readers will find these useful, and we would welcome feedback or comments on the strengths and weaknesses of this new feature (please email either of the editors or [DHC@radcliffepublishing.com](mailto:DHC@radcliffepublishing.com)), as we are still experimenting with the format and style of the feature.

In our usual features, the Practitioner's Blog (Dawood and Mitra, 2012) shows how a collision of cultural beliefs, behaviours and stereotypical assumptions served to obscure the serious nature and severity of a

woman's illness. 'Did You See?' poses a challenge to Eurocentric perspectives from the Antipodes (the word means literally 'the other side', but in this case it refers more simply to the geographical location of New Zealand or *Aotearoa*). It summarises a paper by a geographer who posits the value of adopting a Maori world view, in which the family, and an interactive, socially constructed relationship with the landscape, replace the normal 'Cartesian' dualism of western science (Gerrard, 2012). The New Zealand case may be different in some details, because of the long-standing impact of the 1840 Treaty of Waitangi between the original British colonial power and the ancestors of the Maori of today, supported by the more recent Treaty of Waitangi Act of 1975, which renewed its legislative force, but the moral and intellectual lessons are quite transferable. Many of our 'health belief models' are based on a false assumption of the links between cause and effect, values and actions in the decision-making processes of people. This can and should be challenged more often, to make fairer and better advice giving and healthcare provision and give those with poorer health an opportunity to restore the balance.

Before closing the editorial, let us address the vexed question of terminology and 'political correctness.' At one time, people with disabilities were referred to as 'handicapped.' However, if Wikipedia is a guide to the direction of consensus in language, we might just remark that it is now clear that 'handicapping' (as discussed at some length at <http://en.wikipedia.org/wiki/Handicapping>) is the practice of assigning advantage to different contestants in a competition so as to equalise their chances of winning. This may involve placing an additional physical burden on a more experienced player, or giving the less experienced player a 'start' ahead of the field, to ensure that there is a measure of fairness in the race. In the 2012 London Paralympics, a very complex set of rules was imposed to attempt to even the field between competitors with different levels of physical impairment. It also focused attention on wider attempts and needs to reduce the disability differentially placed on some people by the rules and practices of society to a common base. For people working in the field of 'disability' research, that is to say, looking at the needs of, and provision for, people living with sensory, physical or intellectual impairments and differences, this was a major step forward in the wider acceptance of a need to 'make appropriate adjustments' (as specified in the UK Disability Discrimination Acts of 1995 and 2005 ([www.legislation.gov.uk/ukpga/2005/13/contents](http://www.legislation.gov.uk/ukpga/2005/13/contents))). Perhaps, in the fullness of time, such 'adjustments' will become so familiar that we shall not need to have them explained and justified every time! Meanwhile, the journal will welcome all contributions to the debate and the evidence base.

Finally, we are proud to announce a link-up with the international network 'ETNA', the European Transcultural Nursing Association, whose members can now benefit from reduced individual subscriptions for the journal. We thank their Board and especially one of their founding members, Professor Eileen Richards (Vice-President of ETNA). The news section of the ETNA website ([www.europeantransculturalnurses.eu/news.html](http://www.europeantransculturalnurses.eu/news.html)) provides further details about subscription rates, and encourages members to submit articles for publication in the journal. We would encourage other similar associations who would like a link-up with the journal to get in touch with the editors. Further details about ETNA, for the benefit of non-members, can be found in our Knowledgeshare pages, which continue to provide links to other new resources, and to highlight book reviews and conference reports.

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