

Editorial

The Death of Diversity - mainstreaming and marginalisation? Or metamorphosis and rebirth?

Paula McGee PhD RN RNT MA BA Cert Ed

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

Mark RD Johnson MA PhD Dip HE (Warwick)

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

This is likely to be our final issue as editors of *Diversity and Equality in Health and Care*, as our publishers have taken the commercial decision to cease production – and as yet, we have no takers to continue publication. In setting up this journal in 2004 we took a very broad view of Diversity and Equality issues, which enabled us to attract papers from diverse disciplines and ‘equality strands’ including disability, mental health, race and ethnicity, age, faith and religion. These reflected the key strands of European, Australasian and North American equalities legislation, and partly redressed the balance of studies on inequality which tended to focus on ‘class’ or wealth matters. We also welcomed papers on under-addressed subjects such as endometriosis, learning disabilities, sexual identity and sexual orientation. In doing so we created a platform on which these disparate subjects intersected. We hoped by this means to encourage dialogue between disciplines that perhaps otherwise might have limited interaction. It has been an immense privilege to work with authors from such a wide range of professional disciplines across the world and we are very proud to have been instrumental in facilitating publication of their research. We thank them and our many reviewers. We have enjoyed working with you and we know that you have valued our feedback even when we have had to be tough and say “no”. One author responded to such a message by saying something along the lines of “*thank you for rejecting my paper – it’s much better now*”. We each had copies of this on our office walls for months.

Regular readers will know that this journal was sold last year and the new owners preferred the Open Access Model. We welcomed the challenge (McGee and Johnson 2015). We saw Open Access publishing as a positive step in the democratisation of knowledge because it allows anyone, including members of the public, to access information free of charge without paying journal subscription fees. Thus knowledge is no longer restricted to professionals who can afford to pay or to students using university libraries. We acknowledged that the move to Open Access publishing required new ways of working which we have developed, particularly in terms of asking authors for fees, and, despite teething problems, we have worked hard to make the journal a success.

We also recognised the potential disadvantages of this model of publishing and these have been difficult to address. Research funding is a lottery in which certain fields and subjects are privileged over others. Unfortunately, diversity and equality are (ironically) among the latter group. Individuals and societies

are very keen to be seen as in favour of equality and diversity but paying for these is another matter. Diversity and equality are not sexy issues that create warm feelings or make good television. Quite the opposite. Researching in these fields often exposes the more brutish aspects of human and organisational behaviour. Such exposure makes people uncomfortable. Either they don’t want to believe that others can treat their fellow humans so badly or they are perpetrators and would rather not face the consequences of the exposure of their behaviour. In this context under-addressed subjects may be under-addressed for a reason: no one really wants to pay either for initial or for any research. Quite a lot of research on diversity and equality issues, therefore, may not attract funding or is funded only partly, to shut up critics. Nevertheless lone researchers can produce important results which challenge prevailing orthodoxies. Several of the papers we have published this year have been self-financed. In view of this experience we argue that the Open Access model must become more flexible in accommodating this type of research once peer reviews have taken place.

A second issue is the World Health Organisation’s HINARI Access to Research in Health Programme, set up in 2002. Through this, agreements between major international publishers and designated institutions such as universities and professional training schools enable people in developing countries to access health and social science literature at either very low cost, or for no fee at all (http://www.who.int/hinari/promotional_materials/en/). This programme is extremely important in countries with limited resources. We are proud that Diversity and Equality in Health and Care is one of the journals listed in HINARI as being available in those countries. However, considering HINARI in relation to the Open Access publishing model raises some potential concerns. Throughout our twelve volumes we have made numerous attempts to secure papers from so-called ‘Third-World’ and less-published countries, particularly those in Africa and Asia and we have succeeded at times: see for example Nare 2013 (South Africa), Koss-Chioino & Espinosa 2013 (Puerto Rico), John-Kall & Roberts 2010 (Afghanistan), Roy & Lloyd 2008 (Bangladesh). These papers were published free of charge in accordance with the publishing model of the time. If the author had been required to pay, this would not have happened. The Open Access publishing model therefore offers the possibility that research findings and practice development can be shared by wealthy countries in which people can afford to pay but if the far less wealthy recipients generate new information or practice they cannot afford to publish their findings. We have

therefore also tried to encourage challenging publications from lesser-heard constituencies and areas, even if they might not be technically 'Third World' or developing – so we hope that our readers have benefited from exposure to research conducted in Israel and Arabic-speaking lands, from eastern/central Europe, and the Antipodes. Otherwise the sharing of knowledge risks becoming a form of neo-colonialism through which wealthy and/or dominant countries can continue to promote their own view of the world. Allied to this issue is that of payment for publication by organisations that rely on public donations. Hospices, for example, depend on donations. Members of the public may be very happy to contribute to towards the cost of nursing staff or items that will directly benefit patients. They may be less enthusiastic about paying for publication of research. Thus we leave readers with the hard question of whether it is justifiable to charge every author irrespective of their ability to pay.

Finally, we wish thank all those who have supported our efforts to promote understanding of diversity and equality issues. In particular we thank our authors, some of whom have returned to us several times as their research has developed. We thank our editorial board members and reviewers for their unfailing support and hard work. We thank our readers for their attention and we wish you all well in 2016.

In this issue

We open (and close) with attention to a less fashionable, and often-overlooked form of diversity inequality – the exclusion or marginalisation of, and discrimination against, people with disabilities, whether physical and visible, or mental and intellectual (or 'developmental'). We thank Liz Sayce, Chief Executive of Disability Rights UK, for a trenchant statement of the facts and rights in our Guest Editorial, and we conclude the academic element of the journal with a 'Professional Development' self-teaching, reflective learning item from Qulsom Fazil, our CPD Editor and a specialist lecturer in Disability Studies at Birmingham's Medical School.

In the research papers, we are pleased to present a paper from Germany on a topic that has received minimal attention to date: the plight of refugees fleeing from conflict zones such as Syria or from persecution elsewhere. Many of these individuals need medical attention. Leaving one's home, perhaps with little or no time to prepare, means that the treatment of long term health conditions such as diabetes has to be set aside. The physical hardships and risks associated with migration are detrimental to health and even to life itself. Anne van Dongen and colleagues have examined the implications of migration for those requiring blood transfusion. Variations in blood groups and tissue types between majority and minority populations (an issue which we recently sought to address in a CPD item: Johnson 2015) can have a significant impact on how patients respond to transfusions. This survey of 23 countries reveals a serious lack of blood donors among minority ethnic groups and limited engagement with them to address this issue. This paper marks a first step in developing a strategic approach to ensure that suitable blood supplies are available to all patients who need them.

Our second paper is about work-life balance. This is a very topical issue that has been widely addressed but this paper

offers a different perspective. Makiko Arima and her colleagues provide new insights into the working lives of doctors in Japan showing how current employment practices generate multiple inequalities. Being a doctor there seems incompatible with having children. Lack of childcare and inflexible working hours mean that many women have to give up their careers and men have limited contact with their children. Personal lives and leisure time are also curtailed for both genders. We hope this first study of work-life balance will help to promote discussion about this issue in Japan and lead to the introduction of employment practices which help to retain and develop medical expertise.

In our third paper, Dermot Gorman and Richard Stoker present the outcomes of their survey of the uptake of breast cancer screening among Polish women in one area of Scotland. Their findings reflect the changing nature of migration from being a journey in one direction and usually for life to one in which there is constant interaction with family and friends 'back home'. The ease and affordability of modern travel, mobile phones, the internet, skype, face-time and email all enable people to maintain contact and communicate in real time (Faist, Fauser and Reisenauer 2013). Thus migrants can experience life in both the host and the former country concurrently and move more easily between the two. They can have roots in both settings. Both they and they families 'back home' may benefit through exchanges of advice, support, information and the refashioning of personal identity. In this modern experience of migration, the migrant and the non-migrant can often pick and choose how best to access resources such as health care, especially if access is affected by language and culture. As Gorman and Stoker point out different countries have different approaches, in this case to breast screening. Women may be more comfortable in one setting than in another. Awareness of some of these differences, particularly between developed countries, might save both health services some time and money.

Finally, our Practitioner's Blog deals with gangs and knife crime, a particular problem in many cities. Mary Dawood and Ann-Marie Burr explain how an initiative in London hospitals is offering gang members the chance of a better life. We thank Mary for her work on making Practitioner's Blog such a success over the years. The CPD Feature, by our recently appointed CPD Editor, Qulsom Fazil, picks up again the issue of preparedness to encounter difference in one's clinical and employment practice, in this case relating to working with people with 'learning disabilities'. And, as ever, our KnowledgeShare section contains useful information about human rights and current examples of good practice. We thank Nick Hudson for her sterling work on this feature.

And Finally – we do hope that the fact that our publishers have decided not to continue with the journal will NOT mean that there is no more evidence on diversity and equality in health and care and that researchers, writers, learners, practitioners and educators will still be able to find outlets and sources for their quest to address these vexed and important questions. Marginalisation is one form of death, but maybe – just maybe, our track record over the past 12 years, and the struggle of others, has established that there remains a place for Diversity in the Mainstream, and that it can no longer be ignored as a marginal issue of little consequence for the Majority? Alternatively, we

might try to re-imagine Diversity as a new, more attractive slogan, in the way that 'Diversity' became a replacement and more nuanced way of addressing issues of 'race' or ethnicity.

Maybe, even, Diversity is the new Majority? Let's hope so. We shall leave it to you, our readers, to decide and to make it so! Our best wishes to all our readers and authors for 2016, and the years to come.