

## Editorial

# The ravelled sleeve of care (that knits the world)

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

The international World Shakespeare Festival is part of the cultural Olympiad that accompanies this year's Olympic Games. One of the dominant themes of the festival is the universality of Shakespeare's plays, and the festival is being celebrated across the globe, as well as in the Globe Theatre that stands on the reputed site of his original stage in London. His writing speaks to recognisable truths that transcend language and culture. Current productions in Shakespeare's home town of Stratford-upon-Avon demonstrate that, regardless of the language of the performance, whether it be Southern Sudan Arabic, British (or other) Sign Language, or Gujerati, the setting, the century or the actors' dress, his plots reflect the realities of everyday life. Family feuds, rulers who break the law, greed, lust, old age and human stupidity are all easily recognisable. Every production provides new insights, and recognition of what we now take to be familiar phrases and words that Shakespeare invented, such as 'bandit', 'discontent' and 'pedant' (Mabillard, 2000), and maybe even some cultures and concepts, when these were necessary. Thus we observe that although his *oeuvre* is celebrated as an icon, not all icons are unchanging! Shakespeare's messages are so powerful that some autocratic states have sought to ban his plays lest rebel factions use them to make coded points about perceived injustices. The plots are universal, but the context in which they are performed and the ease with which their themes are translated into other settings make the powerful tremble because inherent in each of these are questions about how people relate, or should relate, to one another.

Care is one aspect of these relational concerns. Human societies depend upon cooperation and cohesion. Looking out for others is essential, although what this entails is mediated by culture and context. The problem with so much of what passes as professional education is that relational concerns are

viewed along narrow ethnocentric lines. Only when the practitioner steps outside the comfort of the familiar do the underlying weaknesses of this situation appear, and it becomes apparent that what has been learned or accepted as evidence or best practice is not immutable. Indeed, Iain Chalmers, the grandparent of evidence-based practice ([www.cochrane.org](http://www.cochrane.org)), recently recalled that when, as a newly qualified doctor, he worked as a volunteer in Palestine he found that much of what he had learned conscientiously at medical school did not seem to apply. He therefore became, in his own words, '*scepticaemic*' about what he had learned (BBC Radio 4, 2012). In other words, as with Shakespeare, the evidence of clinical research, or the processes of healthcare delivery, may indeed be universal, but they are only understandable if they are allowed to be expressed in a culturally specific medium (language) or with other appropriate cultural signifiers. Thus it is also with multicultural medicine or nursing and other caring sciences. Needs are indeed universal, but their expression may be locally highly specific, and the diversity-aware practitioner would be wise to look for the deep structures, and to allow for a multiplicity of styles, and even perhaps the occasional neologism!

*Scepticaemia* is a good word for thinking about diversity and equality in health and social care. The papers in this issue focus on care but seek to challenge prevailing views. All of them offer examples of how and where some translation or reinterpretation of accepted practice has been required in order to make care effective and meet the needs of individuals. Hidden disabilities are a case in point, and we hope that our three linked items will encourage *scepticaemia* in our readers by equipping them to question and challenge prevailing ignorance. Sanderson-Mann *et al* (2012) and Wharrad *et al* (2012) examine the impact and learning needs of nursing students with dyslexia. The

research team that has authored both papers argues that dyslexia may also be associated with enhanced competence or capacity in other valued skills, including intuitive or insightful caring. This thoughtful assessment may prevent worse mistakes and help to counter discrimination by both lecturers and practitioners against people who might be very well suited to the role. Given the issues of hidden learning needs, those of us who teach and train should give careful thought to adapting our existing teaching. It is clear that you don't have to be dyslexic to find handover procedures or report writing daunting, but having dyslexia makes these tasks even more complex. Given the high levels of undeclared or undiagnosed dyslexia, it is probably best that we should all work to some common denominator of competence to ensure patient safety. We should also note that the research team responsible for these two papers also shares our commitment to promoting 'open learning' sources and enhanced professional learning (see, for example, the 'SCOOTER' resources on sickle cell highlighted by Rolfe *et al* (2012) and others regularly listed in our 'Knowledge-share' section).

Alongside these two papers, Nick Gee presents a Continuing Professional Development educational feature about other hidden disabilities such as Asperger's syndrome and dyscalculia (Gee, 2012). This overview also includes learning resources and some wise words of advice. If you cannot see a disability, and maybe don't know how to describe or name it, it is hard to devise strategies or learning aids to support learners, and we hope that this quick guide will provide all teachers with some helpful insights. We believe that the use of non-linear, semi-pictorial presentation is innovative and may prove helpful as a method which could be more accessible to some learners who are disadvantaged by formal and highly verbal routine styles. We would very much appreciate feedback from our readers if you found this helpful, too.

(In passing, for those who pride themselves on accuracy and pedantry, and might legitimately wish to insist on proper spelling in student work and clinical notes, the headline of this Editorial does not contain a mis-spelling. Shakespeare did not write 'sleeve' as in garment. The 'sleave' referred to is otherwise known as a 'skein' of yarn!)

Hussein and Manthorpe (2012) continue their series of findings from analysis of a national data set in England, and add to our knowledge about the social care workforce by turning the spotlight on those who support the vast army of (unpaid) carers, or as the authors describe them, *family carers*, accepting that these will include some friends and neighbours who may also provide support in unpaid roles. This intermediate tier, consisting of individuals who are neither professional care workers nor social workers, has a crucial and often unrecognised role to play, enabling

the family carer to function, but has not apparently been studied in any depth. If the ideals of the Carers Charter ([www.Carers.org](http://www.Carers.org)) and the aspirations of other manifestos such as the National Black Carers and Carers Workers Network (Afiya Trust, 2008) are to be fulfilled, it is clear that this sector will also need help and support, and work on its diversity profile.

Williamson and Sacranie (2012) have collaborated to present a paper that deals with the concerns of the ultimate caregivers, namely nursing mothers. They explore British Muslim mothers' experiences of breastfeeding, offering additional insights in terms of the spiritual construction of this act, and the rewards that it brings. The sample includes an interesting cross-section of cultural backgrounds. The unifying features of their informants' experiences were the Islamic faith and motherhood. They find that there is religious as well as clinical support for the practice, and show how an understanding of people's faith can help the practitioner to support the carer and avoid other stereotypical understandings. It is important to recognise that, for many, a personal spirituality is entirely compatible with the most technologically advanced or scientifically complex understanding. The paper highlights the fact that a religion is not 'a culture', even if it can inform cultures.

Finally, in our research papers, and returning to the concerns of people with specific intellectual impairments, Cuadra (2012) presents her reflections on the issues raised in seeking to conduct research on the needs of children and adolescents with functional, cognitive and developmental disabilities from a multicultural perspective. Her finding is that much research and service planning is fundamentally ethnocentric, and often uses derogatory or pejorative language to describe others. There are often two competing paradigms, namely the *culturalist* and the *rights-based*, which are not always congruent, especially when some cultures are seen as deviant or do not easily fit into a *rights-based* approach where rights may be in competition. Cuadra's suggestion that access is a process, with a number of key stages, is also helpful in disentangling the points at which various barriers or impediments to fair and appropriate access to support require differing interventions to assure a satisfactory outcome for minority and disadvantaged people, since intellectual or physical disabilities also intersect with faith, culture and all the other elements of diversity.

Of course, this issue also contains our usual features, including a challenging and thoughtful Guest Editorial from Suki Desai, who reflects on the changing landscape of social policy and the looming impact of 'cohort' aging of the BME population of former migrants in Britain, as the expectations and practicalities of modern life have to be met under an increasingly constrained 'big-society' model of welfare

(Desai, 2012). In 'Did You See?', another member of our editorial team, Nisha Dogra, takes a new look at diversity, following on the mantra (which we support) of 'not about us without us', namely the 'emic' insights that those within a group can have rather than the outsider observer's perspective. She notes that there is no single *emic* truth either. Those with a disease or condition are also all different both clinically and in terms of personality, even if they are often lumped together as 'fellow sufferers'! As Nisha writes, 'Why is caring so often perceived to be about instinctively knowing what someone needs? Why can't we just ask?' This includes how you wish to be seen and treated in gender terms, as our Practitioner's Blog movingly illustrates. Coincidentally, the World Professional Association for Transgender Health has recently released a revised edition of its Standards of Care (SOC) for Transgender and Gender Non-Conforming People in September 2011. The full text is available at [www.wpath.org/documents/Standards%20of%20Care\\_Full\\_Book\\_1g-1.pdf](http://www.wpath.org/documents/Standards%20of%20Care_Full_Book_1g-1.pdf). These Standards of Care provide clear statements that gender non-conformity is not pathological, as well as guidance with regard to mental health, psychotherapy, hormones and surgery, and advice that changes no longer have to be binary (from one gender extreme to the other), thus facilitating the provision of services for gender-queer/two-spirit people. More information is available on their website ([www.wpath.org/about\\_wpath.cfm](http://www.wpath.org/about_wpath.cfm)).

Our 'Knowledgeshare' section continues to provide links to other new resources, and to highlight book reviews and conference reports. Finally, in this context, let us welcome another new entrant to the scene, namely the 'Health Equalities' e-magazine, a twice-yearly round-up of articles compiled primarily for those in North-West England by the former Black Health Agency, now the BHA for equality in health and social care ([www.thebha.org.uk](http://www.thebha.org.uk)).

## REFERENCES

- Afiya Trust (2008) *Beyond We Care Too: putting black carers in the picture*. London: Afiya Trust for the National Black Carers and Carers Workers Network. [www.afiya-trust.org](http://www.afiya-trust.org)
- BBC Radio 4 (2012) *Interview for 'Life Scientific' series*. Jim Al-Khalili and Iain Chalmers, 28 February 2012. [www.bbc.co.uk/podcasts/series/tls](http://www.bbc.co.uk/podcasts/series/tls)
- Björngren Cuadra C (2012) A study of approaches within research on problems of access to services for children and adolescents with functional, cognitive and developmental disabilities from a multicultural perspective. *Diversity and Equality in Health and Care* 9(2):125–40.
- Desai S (2012) Will it ever change? The continuing unmet needs of older black and ethnic minority people and social care. *Diversity and Equality in Health and Care* 9(2):85–7.
- Gee N (2012) Disability and difference in higher education: be prepared for what you can't know. *Diversity and Equality in Health and Care* 9(2):151–5.
- Hussein S and Manthorpe J (2012) The diversity of staff supporting family carers in England: findings from an analysis of a national data set. *Diversity and Equality in Health and Care* 9(2):101–11.
- Mabillard A (2000) *Words Shakespeare Invented*. [www.shakespeare-online.com/biography/wordsinvented.html](http://www.shakespeare-online.com/biography/wordsinvented.html) (accessed 23 April 2012).
- Rolfe V, Fowler M and Dyson SM (2012) Sickle cell in the university curriculum: a survey assessing demand for open-access educational materials in a constructed community of interest. *Diversity in Health and Care* 8(4):239–49.
- Sanderson-Mann J, Wharrad HJ and McCandless F (2012) An empirical exploration of the impact of dyslexia on placement learning, and a comparison with non-dyslexic students. *Diversity and Equality in Health and Care* 9(2): 89–99.
- Wharrad HJ, Sanderson-Mann J, McCandless F and Riley F (2012) Using reusable learning objects to raise awareness and disseminate research findings about the impact of dyslexia on placement-based learning. *Diversity and Equality in Health and Care* 9(2):141–9.
- Williamson IR and Sacranie SM (2012) Nourishing body and spirit: exploring British Muslim mothers' constructions and experiences of breastfeeding. *Diversity and Equality in Health and Care* 9(2):113–23.

